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ABSTRACT

Fourteen papers delivered at the 1976 national forum on residential services sponsored by the National Association for Retarded Citizens are presented. Among topics addressed are historical perspectives on institutional change and normalization, a continuum of residential alternatives, deinstitutionalization, funding resources, funding strategies, management and administrative issues, laws and regulations, and accountability and monitoring. Also reviewed are five current program models: the Elisabeth Ludeman Developmental Center, a public institution; group homes sponsored by the Pennsylvania Department of Public Welfare; the Eastern Nebraska Community Office of Retardation, a regional community model; foster homes; and Innisfree, a village integrating the retarded with the nonretarded. Appended are a bibliography on community based residential services and a list of participants in the conference. (CL)

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1976

National Forum on
Residential Services

National Association for Retarded Citizens
NARC Research and Demonstration Institute

EC100873

The Forum was partly underwritten by a friend of NARC in memory of John Walter Saladine and Dorothy Bill Saladine and their love for their grandson, with the hope that this forum stimulates humane and innovative solutions to complex problems.

NARC Research and Demonstration Institute
National Association for Retarded Citizens
2709 Avenue E East, P.O. Box 6109
Arlington, Texas 76011

national association
for retarded citizens

A National Forum on Residential Services

December 3-4, 1976

NEW ORLEANS

Contents

FACULTY iii

INTRODUCTION 1
Frank Menolascino

HISTORICAL PERSPECTIVES 5
Eleanor Elkin

COMPREHENSIVE SYSTEMS 13
John McGee/Wade Hitzing

DEINSTITUTIONALIZATION 27
Fred Krause

FUNDING RESOURCES 37
Susan Weiss Manes

FUNDING STRATEGIES 49
Rita Charron

ADMINISTRATIVE ISSUES 63
Dennis Popp

LAWS AND REGULATIONS 85
Paul Friedman

ACCOUNTABILITY AND MONITORING 97
Ed Skarnulis

PUBLIC INSTITUTIONS 107
George Garland

GROUP HOMES 117
Mel Knowlton

A COMMUNITY SYSTEM 125
Barry Lamont

FOSTER FAMILIES 135
Gerald Provencal

THE VILLAGE 157
Heinz Kramp

SUMMARY AND TRENDS 165
Frank Menolascino

BIBLIOGRAPHY 191

PARTICIPANTS 205

Faculty

Rita Charron
Director of Programs for the
Mentally Retarded
Tri-County Community Mental
Health Board
606 West Shiawassee Street
Lansing, Michigan 48933
(517) 487-6500

Eleanor S. Elkin
Chairman, NARC Residential
Services & Facilities Committee
5555 Wissahickon Avenue
Stafford House - Apt. #915
Philadelphia, Pennsylvania 19144
(215) 438-1188

Paul R. Friedman, J.D.
Managing Attorney
Mental Health Law Project
1751 N Street N.W.
Washington, D.C. 20036
(202) 467-5730

George F. Garland
Director of Residential Services
Elisabeth Ludeman Developmental Center
114 North Orchard Drive
Park Forest, Illinois 60466
(312) 747-8100

Mel Knowlton
Director, Bureau of Community
Residential Services
Department of Public Welfare
Office of Mental Retardation
Harrisburg, Pennsylvania 17108
(717) 783-8300

Heinz Kramp
Director and Co-Founder
Innisfree Village
Innisfree Route #2
Box 506
Crozet, Virginia 22932
(703) 823-5088

Fred J. Krause
Executive Director
President's Committee on
Mental Retardation
Washington, D.C. 20201
(202) 245-7634

Barry H. Lamont
Director of Residential Services
Eastern Nebraska Community
Office of Retardation (ENCOR)
885 South 72nd Street
Omaha, Nebraska 68114
(402) 444-6500

Frank J. Menolascino, M.D.
Professor of Psychiatry and
Pediatrics
Vice Chairman, Department of
Psychiatry
University of Nebraska
College of Medicine
602 South 45th Street
Omaha, Nebraska 68106
(402) 541-4533

John McGee, Ph.D.
Director, Center for the Development of Community Alternative
Service Systems (CASS)
444 South 44th Street
Omaha, Nebraska 68131
(402) 541-4730

Dennis Popp
Coordinator
Developmental Disabilities Services
Division of Mental Health and
Mental Retardation
State Office Building, 5th Floor
Topeka, Kansas 66612
(913) 296-3471

Jeanne Potak
Coordinator of Mental Retardation
Services
Lehigh County Mental Health/
Mental Retardation Center
Americus Hotel, 8th Floor
6th & Hamilton Streets
Allentown, Pennsylvania 18101

Gerald Provencal
Director of Programs
Macomb-Oakland Regional Center
16200 Nineteen Mile Road
Mt. Clemens, Michigan 48043
(313) 286-8400

Edward R. Skarnulis
Assistant Professor and
Clinic Manager
University of Nebraska
Medical Center
Department of Family Practice
42nd and Dewey Streets
Omaha, Nebraska 68105
(402) 541-4979

Susan Weiss Manes
Assistant Director
NARC Governmental Affairs Office
1522 K Street, Suite 516
Washington, D.C. 20005
(202) 785-3388

1

Introduction

FRANK J. MENOLASCINO

Recent court decisions, accreditation standards and federal regulations are demanding a reduction of public institutional populations along with improvements in the quality of residential programs. A lack of adequately described alternative models places state planners and consumer advocates in the position of making poorly informed decisions. State agencies have frequently committed enormous fiscal resources to residential services plans which later proved ineffective, disruptive, contradictory and, in some cases, illegal because the planners did not have access to a variety of viable options among appropriate alternative service models.

The format and content of this National Forum on Residential Services is designed to have maximum impact on the problems and dilemmas faced by state and local planners of mental retardation services. format

Our overall goal is to provide the basic information which is necessary to develop an action plan for implementing a comprehensive system of residential services. Specific presentations will highlight this information in a manner wherein it could be directly utilized on behalf of our retarded citizens. Then a series of "showcases" will illustrate the details of five current program models for delivering residential services within a variety of ideological and geographical population guidelines. goal

I am very pleased to note the large number (250) in attendance at this Forum, since I recall that 10 to 15 years ago, if one scheduled such a forum you might find about 20 people in attendance. There was precious little interest then and unfortunately this reflected precious little concern.

At that time we "knew" the answer and we--the doctors--certainly "knew" the "answer." Because the citizen who happened to be labeled "retarded" was, because of that symptom, indeed abnormal, and we had places to send them to be "...with their own kind." This model and posture of professional-public thinking persisted in this country from 1910 until about 25 years ago. There were no voices to speak of alternatives, hope or compassion.

cooperation

I am also pleased to note that in our attendance there are state and local planners and representatives from all three levels (local, state and national) of our ARC movement. There also are present a number of elected officials such as senators from many of our states. Welcome to all of you! We, as an organization, have always been pleased to work with a coming-together of diverse groups. This coming-together for common interests has become a knowing-together, and it has been a key ingredient of the work of NARC these last 26 years.

The rise of the National Association for Retarded Citizens in 1950 brought both the impact of advocates and the beginning of an ongoing concern and push for residential alternatives. The alternatives include some persistent themes of help--which Eleanor Elkin will historically review for us in the first major presentation--such as: What are the more modern and humane residential approaches? What can we do? How can we do it? Let's get it done!

key issues

In my opinion the issue of residential services is, without question, the key one in the field of mental retardation in our country today. From the viewpoints of interest on the part of retarded citizens, their advocates, public officials and the financial-political repercussions--every other issue in this area pales by comparison. From our perspective as advocates of retarded citizens--residential services are currently the same cutting edge as were the Opportunity Centers in the early fifties. The Opportunity Centers were our first candles of hope for the retarded citizens of this country. In the early fifties, when the education establishment of our nation would not, because of attitudinal blindspots, provide training opportunities for retarded citizens, it was the ARC movement that did provide the Opportunity Centers. They became the candles of hope (and help) which lit the road to classes for the trainable, then the more global special education thrusts and now with the right-to-education national legislation--Thank God! for the Pennsylvania Association for Retarded Citizens--this has become a generic service for every citizen in this country who happens to be retarded.

That same approach, that same fervor, that same search for viable models of help is now present in the push for modern residential services today.

Indeed, group homes are the Opportunity Centers of the seventies, and they have become the candles of hope which will illuminate alternative pathways to and out of the institutions which have dimmed the developmental horizons of many of America's present generation of retarded citizens. The questions of how, when and where to "do it" tend to haunt us. Similar questions were splendidly discussed by Dr. Elizabeth Boggs in the First Plenary Session on residential services at our 1976 National Convention in Indianapolis. She gave one of the finest presentations I've heard on mental retardation in the last 15 years. This pioneering lady of NARC had the "audacity" to question the modern concept of normalization and improve on its utilization value--rather than the catch phrase it has so often become. She spoke, as a parent of a retarded citizen, to the common sense underpinnings of the normalization concept and its impact(s) on the opportunities available for the least restrictive residential environments possible for the freedom and development of all of our retarded citizens. She underscored that we must match a series of residential options to the wide variety of personal-social needs of our retarded citizens.

normalization

Many of the persistent questions focus on the need for evolving models of residential services which do "work." Yes, we have had benchmark documents which presented overviews of the state of the art in residential services. One excellent example was the publication of the President's Committee on Mental Retardation's Changing Patterns in Residential Services in 1969 (and its new edition in 1976). In the 1969 document the presentation by Dr. Gunnar Dybwad focused on the roadblocks which have stifled progress in evolving modern residential programs for retarded individuals. In 1976 those same roadblocks are still present. Yet we now do have models that work, and our public information efforts have appreciably altered professional and general public attitudes toward our retarded citizens. Indeed, a recent report of the President's Committee on Mental Retardation (People Live in Houses) clearly documents modern models of residential services which have served, and are serving, retarded citizens very effectively!

PCMR

I think this Forum will provide all of us an opportunity to lean back, interact with the presentors and expand our minds. Reflect on these presentations--on this vital topic--and then do something!

Our first presentation will be by Mrs. Eleanor Elkin, a dear friend of mine and of the retarded citizens of this country. Hers has been a total, ongoing commitment to service and advocacy. She is a past President of NARC and is the current Chairperson of the NARC Residential Services

Committee. She has been the driving force in the initiation and finalization of this Residential Forum. Her presentation will trace the historical perspective of our ARC movement concerning residential alternatives, past and present: what happened, how it happened and our current posture on this most vital dimension of our movement's ongoing commitment to alleviate the symptom of mental retardation.

Historical Perspectives

ELEANOR S. ELKIN

Being asked to talk about history can make a person uncomfortable. We don't like to admit we've been around long enough to talk about history, but I have a measuring stick of my age. It was given to me by a very wise woman. A committee of junior women were discussing whether or not you could continue as a member of a junior women's club if you were past 30 - a very serious problem. This lady stopped us, saying, "Just remember, you're only old when a new idea hurts." When change starts hurting, I stop, re-examine the issues and my motives and ask myself if I am young enough to meet the challenge.

The NARC scene.... Perhaps it began when a mother put an advertisement in a newspaper asking other parents of retarded children to come to her home to talk about their children. They were frustrated and upset because the schools had "excluded" or "excused" their children. Nursery schools and camps would not accept them, and services for the blind, deaf or crippled children were closed to those who were also retarded.

parents

For them the future must have seemed dark indeed as they looked ahead and saw only the institution looming at the end of a very short road. Most people believed that was the way it had to be, but these parents were determined to obtain acceptance and a place in the community for mentally retarded persons, so that they could walk in dignity with their families and their friends.

single
service

They got together - they laid plans - they talked about retarded children to everybody they could get to listen. Some of their neighbors called them "dedicated" - and brave. Some officials called them aggressive - and emotional - and interferring.

But...they were heard...in Seattle, in Columbus, in Montclair and in New York.

They even began to hear each other and to realize that if they could join together, they would be able to speak with strength.

NARC origin

In 1950 about 40 "parents and friends of the mentally retarded" gathered in Minneapolis, forming NARC, and pledging themselves to become spokesmen for a better life for all retarded persons.

The early business of the association was carried on solely by volunteers. Thousands of letters were written to parents in response to their calls for help and to fellow citizens asking for their understanding and support. Who knows how many cakes were baked to get funds to start nursery classes in church basements.

first office

When they finally were able to open an office with a small staff, the association launched a crusade for public understanding and acceptance of mentally retarded persons and for the provision of necessary services. Their voices proclaiming "retarded children can be helped" were heard throughout this country.

These pioneers were successful in many of their efforts, such as securing programs for children who were labeled "uneducable" and so, rejected by the public schools; promoting better handling of "new" parents by the family physician; and obtaining programs for those persons termed "infeasible" for training by the vocational rehabilitation authorities.

legislation

They traveled to Washington and state capitols for special hearings and private conferences. They were instrumental in the formation of diagnostic and evaluation clinics, recreation programs and counseling.

In 1962 they were recognized before the whole world when NARC received the First International Award for Outstanding Achievement in Leadership from the Joseph P. Kennedy, Jr. Foundation.

Yet parents could not really rejoice in their successes because their hearts still held the chilling fear of the future. What would become of the handicapped member of their family when they were dead? They must learn more about this place where many of their neighbors' children already resided.

purpose

Of course, there had always been an interest in institutions. The NARC Constitution lists nine purposes for the Association's existence. The first, the very first, of these purposes is:

> "To promote the general welfare of the mentally retarded of all ages everywhere: at home, in the communities, in institutions, and in public, private and religious schools."

institutions

Several of the charter members of NARC belonged to units that were formed of parents whose children resided in a specific institution. The activities of these units were mainly benevolent. They gave picnics and parties, and obtained special items for the residents. However, few institutions boasted such a parents' group, and even fewer had, or wanted, a volunteer program. Superintendents at that time did not welcome this "outside interference" and discouraged them, claiming the necessity to protect the privacy of the residents and their families.

committee

Early, committees were formed, called Institutions Committees of NARC. They were concerned with finding the way into the institutions, both for themselves and for retarded people. They advised parents to make application for their child to enter the institution as "insurance" in case of their death. After all, who could afford a private "school?"....And the waiting list was five years long, almost everywhere in the country. They made large donations to institutions for swimming pools and circuses and Christmas presents. They collected old clothing (I've never seen such unbelievably moth-eaten and dirty clothing) and dolls and coloring books - lots and lots of coloring books - for the residents. They delivered these gifts to the institution - that's how they got inside - and they didn't like what they saw. And they said, "Something has to be done."

institutional change

In April of 1958 the NARC Board of Directors adopted a policy statement that future plans for state institutions should contain "plans for housing no more than 1,500 persons at each institution." Progress? It was. Many of them had 3,000 to 6,000. The statement also called for plans for establishing such institutions close to population centers, preferably in those communities in which there were universities or medical schools.

In the publication, Decade of Decision, an evaluation report prepared for the 1960 White House Conference on Children and Youth, NARC noted that the task ahead required the "projections of future need for residential care of the severely retarded based on analysis of changing trends in the characteristics of children for whom such care is sought." It also stated ..."The period 1950 to 1960 has seen the advent of both tranquilizers and TV in most institutions, on the whole for the better, although not without certain attendant hazards for those who mostly sit and wait."

survey

In 1963 the NARC Residential Care Committee (note the name change, but it would be another five or six years before it would become the Residential Services Committee) conducted a "Survey of State Residential Institutions." It had as its objective better understanding by parents of the problems and needs of the institution and better understanding by the institution's personnel of the parents' problems and needs. The report was presented and discussed before a packed house at the NARC convention. It revealed great differences in the types and quality of institutions. Many NARC members became very concerned about what the report indicated might be happening to children and adults living in institutions.

legislation

State and local committees got their legislators to tour institutions with them. With the legislators they got into areas of the institutions that parents and volunteers had not seen before and what they saw made them cry. Their solution to the reduction of waiting lists and the overcrowding and the lack of programs was to work to build more institutions. Surely the new institutions would bring a better life to those people who would move into them.

Members of President Kennedy's Panel on Mental Retardation went to Europe and visited residential facilities there. They brought back to us pictures and reports of hostels and halfway houses and institutions that looked pleasant. Surely, it could happen here.

standards

The AAMD's Standards for State Residential Institutions for the Mentally Retarded, published in 1964, presented minimal standards thought to be generally attainable within five to ten years and to be usable as a basis for future evaluation of 134 state institutions. But these "peer group" evaluations were considered confidential and were not released to ARC people unless the superintendent so chose. Few ever reached us.

definition

In 1965 the NARC Board of Directors, in its charge to the Residential Care Committee, defined residential care, "to include any facility which provides 24-hour care for the mentally retarded, whether in a large institution, school, hospital, regional center, boarding home, nursing home, hostel or halfway house, under private or public auspices." In this charge they also stated, "Residential care should be considered a part of, rather than a substitute for, community services for the retarded. A residential facility and other agencies within the community should constitute a cooperative team serving the retarded individual and his family." Some states were beginning to establish regional centers. Some states, particularly their Residential Services Committee members, talked about designing better residential facilities where people could be housed and served in smaller groups.

ideas from Europe

Through its Rosemary F. Dybwad Awards for travel, NARC began to send both volunteers and professionals to study the residential services programs in Europe, particularly in the Scandinavian countries. Many came back with fire in their eyes and exciting accounts, not only of institutions, with bedrooms for two people, furnished with regular furniture and decorated with bright, cheerful colors, but of retarded individuals living in apartments and homes - right in the neighborhood with the other folks.

The Rosemary F. Dybwad Awards were also helpful in bringing experts from Denmark, Sweden and England to help us improve our residential services. They were horrified at what they saw. An official from Denmark told the press that in Denmark they treat their cattle better than we treat our institutionalized people. That hurt. That upset us.

More committees made more tours of the institutions, and they were shocked at what they still saw. Those who had seen a cattle barn in Denmark knew that our friend told the truth. Something had to be done about the dreadful, dehumanizing conditions in which we were allowing people to live.

national planning committee

In 1966 NARC adopted as a prime objective the development of a "long-term program to achieve: (a) a marked improvement in residential facilities and programs; and (b) a better public understanding of the need for improved residential care of retarded persons." As a strategy for meeting that objective, NARC joined with the American Association on Mental Deficiency, United Cerebral Palsy Associations, American Psychiatric Association and the Council for Exceptional Children to organize the National Planning Committee on Accreditation of Residential Centers for the Retarded. This was the group that established the Accreditation Council for Facilities for the Mentally Retarded (now Developmentally Disabled has been added) within the Joint Commission on Accreditation of Hospitals. NARC is represented on the Council by two members.

normalization

In 1968 NARC issued its Policy Statements on Residential Care and launched a " Crusade for Change" in residential services. The publication, in 1969, of The President's Committee on Mental Retardation's monograph, Changing Patterns in Residential Services for the Mentally Retarded, brought Bengt Nirje's normalization principle to America. And to refresh you, it says: "The normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."

I have to make a comment here because it was said that normalization was challenged, and everything should always be questioned. This year a symposium on Integration and Normalization was sponsored by NARC for the

International League of Societies for the Mentally Handicapped. One very interesting thought was repeated several times. Normalization is an idea; it's a tool - it's a tool that was developed to help us undo the terrible dehumanization to which we have subjected people in our residential facilities. If we do our job right in a few years we won't need to worry about misunderstanding of the word. We won't need it because we won't need that tool any more. Hold that thought...a very important one.

The acceptance of the normalization principle marked a turn-around in our thinking and our actions.

normal
patterns

Also in 1969 the International League of Societies for the Mentally Handicapped conducted a symposium on residential services in Frankfurt, Germany, in which 13 countries, including the United States and NARC, participated. They concluded: "Retarded children and adults...should be helped to live as normal a life as possible. The structuring of routines, the 'form of life' and the nature of the physical environment should approximate the normal cultural pattern as much as possible. The hospital model is inappropriate for residential services for most of the mentally retarded."

community-
based

The next year, 1970, The President's Committee in An Action Policy Proposal supported the principle that new facilities should be located within the community served and provide for normal contacts with the life of the community.

The President's Task Force on the Mentally Handicapped, in 1971, warmly endorsed the replacing of existing institutions by smaller home-like units located within the community.

In October, 1972 the NARC, in annual delegate convention assembled in Montreal, Canada, in connection with the International Congress, adopted the following resolution:

1972
resolution

> "BE IT RESOLVED...That the National Association for Retarded Children recommends that the public interest requires that additional residential facilities for the mentally retarded must be constructed, purchased or leased.
>
> "BE IT FURTHER RESOLVED, that the National Association for Retarded Children recommends that such residential facilities consist of small living units, each replicating a normal home environment to the closest extent possible.

> "BE IT FURTHER RESOLVED, that the National Association for Retarded Children recommends that such residential facilities take absolute precedence over further capital investments in existing or new large scale 'institutions'..."

And the turn-around was complete. Now Residential Services Committees began seeking the way out of the institution and the establishment of quality special living arrangements in the community.

In 1973 NARC published The Right to Choose to help them. Many different communities are providing many different kinds of residences. No two are alike because they are reflections of the individuals who live in them.

However, not everyone was pleased with this progress. Some people felt that it was a step backwards and that mentally retarded children and adults living in institutions were being abandoned. The movement of individuals from the institution into desirable places in the community was (and is) slow. Careful planning on the part of the community, institution and family is necessary to help the retarded person live successfully in the community. When movement of large numbers of persons from the institutions was rapid, it was usually unsuccessful...sometimes disastrous. Responsible, caring people were horrified at the irresponsible "dumping" of mentally retarded boys and girls, men and women into the community, often in substandard boarding or nursing homes, without arranging for necessary program services to help them achieve and maintain their fullest independence and ability. With the availability of federal dollars through Medicaid, many nursing homes and intermediate care facilities began accepting residents of institutions. In some states this was their deinstitutionalization program...shifting human beings from big facilities to smaller buildings - never mind their needs or desires. In response to this situation NARC held a National Symposium on Nursing Homes, in May 1975, and in October of that year issued Nursing Homes in the System of Residential Services: A Position Statement. The position statement enunciates basic guiding principles which can be used by parents and professionals to assess the appropriateness of nursing home settings for mentally retarded persons.

careful planning

medicaid

Still, there was confusion and misunderstanding about NARC's position regarding residential services. The membership, at the 1975 annual convention, directed the Residential Services and Facilities Committee to reexamine and update NARC's position on various issues and problems

residential
options

related to residential services. The publication, Residential Services: Position Statements of the National Association for Retarded Citizens, was adopted by the Board of Directors in October 1976 and is included in your Forum packet. It concludes: "It is the right of handicapped individuals, including mentally retarded persons, to live their lives as normally as possible within the community. Every state and community must give precedence to the establishment of a variety of living arrangements and the necessary support and program services within the community."

accreditation

And it also says: "...adequate funds must be provided to assure that community programs become financially stable and that existing public facilities are able to meet accreditation standards..."

And further: "...there is no difference in the rights and entitlements of retarded persons, no matter where they live or whether those residential facilities are publicly or privately owned. The ARC movement is charged with the continuing duty of monitoring the quality of life and the dignity of individual programs wherever they may occur."

obstacles

It isn't easy. There are unknowns and obstacles. There are zoning problems and worried neighbors. There are unions and institutional suppliers. Some of the bitterest opposition comes from parents who are concerned about the future and who believe their children need the protection of an institution. Position statements do not alleviate their fears or solve their problems.

We accept the challenge. We've never been afraid of change and opposition to change. It is the story of the fight for a full life with dignity for our children, neighbors and friends who happen to be mentally retarded.

Today, together, we begin a new chapter in that story.

Comprehensive Systems

JOHN McGEE
WADE HITZING

Many people have asked why there are still nearly 154,000 mentally retarded citizens in state institutions. Federal District Court Judge Orrin G. Judd answered this question when speaking of the Willowbrook lawsuit. He said, "In most cases there simply is no other place for the residents to go."

This straightforward reply is a fair description of the status of residential alternatives for many mentally retarded citizens in the United States today. For the 154,000 institutionalized, mentally retarded citizens in this country there is often nowhere else to go. Yet, there is much discussion concerning a continuum of residential programs which has evolved in recent years, a continuum which is presumed to be capable of meeting the residential needs of all mentally retarded citizens.

In this paper we have been asked to describe this comprehensive continuum of residential alternatives. To do this we will:

1. Examine the impact that values have on the development of residential alternatives;
2. Describe the current continuum of alternative residential environments;
3. Analyze the implications of this continuum;
4. Describe an alternative approach which is based on an array of **services** rather than **environmental** options; and

5. Analyze the implications of this alternative, especially with respect to future planning.

human values

It is important to note that we are describing and analyzing both the current, widely accepted continuum of alternatives as well as an alternative approach to the development of residential services. We feel strongly that if professionals, consumer advocates and consumers critically question the human values upon which services are built, there will be a substantial shift away from current trends.

BELIEFS

All human services are based on belief systems, either conscious or unconscious, that shape the quality and type of services to citizens who are disabled or handicapped. Quite often these beliefs are unconscious. We rarely question these beliefs; we almost never ask "Why?"

> Recently a county board invested $600,000 in new construction at the county home. When asked why the county would spend so much money in segregating people, one of the board members replied, "All they need is plenty of open space, clothing, a hot meal and a bed..."

Such statements appear ludicrous, yet they are quite common.

segregation

Traditional belief systems have resulted in human service systems based on segregated settings, environments and architecture. We have usually assumed that people with special needs require separate, special places to live and be served in. Our beliefs have been translated into environmental terms: old people belong in nursing homes, retarded people in institutions, handicapped people should live in villages, etc.

Such segregating architectural approaches have been "justified" by various rationalizations such as: economy, safety, protection and stability. Such rationalizations serve to reinforce the concept that it is necessary to segregate people with special needs rather than integrate them into community life.

THE CONTINUUM OF RESIDENTIAL ENVIRONMENTS

Our nation's response to the deinstitutionalization mandate has resulted in what can be described as a continuum of different residential environments. These environments can be placed on a continuum which ranges from more restrictive to less restrictive. There are various broad environmental areas on the continuum which can be described. These environments can be analyzed in relation to their degree of restrictiveness or in relation to how they tend to integrate a person into community life.

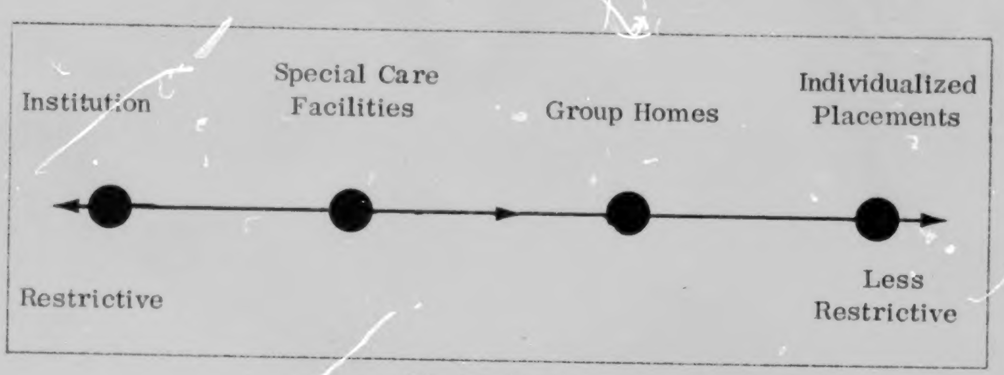


Figure #1

There are many variations of these four environments; however, in general, they are representative of the major service responses the system has made to meet the residential needs of disabled citizens over the last decade.

INSTITUTIONS

"This environmental model consists of intermediate and large units usually physically and socially segregated from the surrounding community. The model generally restricts the client to the segregated facilities although there may be some social, occupational or educational integration within the surrounding community" (James Budde, ALERT, Kansas University, 1975).

"The term institution refers to a deindividualizing residence in which persons are congregated in numbers distinctly larger than might be found in a large family; in which they are highly regimented; in which the physical and social environment aims at a lowest common denominator; and in which all or most of the transactions of daily life are carried on under one roof, on one campus or in a largely segregated fashion" (W. Wolfensberger. The Principle of Normalization in Human Services. National Institute on Mental Retardation, Toronto, Canada, 1972).

"...placement of the mentally retarded outside their natural homes into any living arrangement not of their own choice is institutionalization..." (James Clements, "Appropriateness of nursing home settings," in Nursing Homes in the System of Residential Services, National Association for Retarded Citizens, 1975).

SPECIAL NEEDS FACILITIES

"This environmental model consists of intermediate or small units that are often physically integrated into, but socially segregated from, the surrounding community by numerous restrictions, but there is some social, occupational and educational integration. Most services' functions are consolidated within this model for the reasons such as expedience, economy of organization or due to the perceived inability of the clients to function in a more integrated manner" (James Budde, ALERT, Kansas University, 1975).

Intermediate Care Facilities

title XIX

"According to the federal law, an ICF is defined as an institution which provides 'health related or rehabilitative care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing home is designed to provide, but who, because of their physical or mental condition, require care and services above the level of board and room.'

"...the largest nursing homes in this country are what we formerly called state mental retardation institutions. Yes, the old state-operated, multipurpose institution for the mentally retarded. I wonder, is it better to call them 'skilled nursing facilities' or 'intermediate care facilities' for the mentally retarded?" (Susan Weiss Manes, Nursing Homes in the System of Residential Services, National Association for Retarded Citizens, 1975).

GROUP HOMES

integration

"This environmental model consists of small service units that are usually physically and socially integrated into the surrounding community. The model results in integration as a function of the community's cultural, social, occupational and educational attitudes. Services are usually individualized and the foremost emphasis is on the client. If restrictions are needed, attempts are made to make them on an individual basis and for only as long as it is necessary for the individual's development. There are usually no more than eight to ten clients per home" (James Budde, ALERT, Kansas University, 1975).

"A residential environment where the individual enters...a home atmosphere...(ensuring) that residents lead 'normal lives' and participate in community life outside the house. The basic philosophy behind group homes, maximizing community contact for disabled persons, requires a day program, a vocational and/or educational experience outside and away from the residence" (Robert Goodfellow. Group Homes: One Alternative, Center on Human Policy, Syracuse, New York, 1974).

"A group home is a facility located in a residential community providing shelter and/or rehabilitation for (individuals) who, for various reasons, cannot reside in their natural home...The goal of the service is to return home, other placement or emancipation, depending upon the age of the (person) and the circumstances of his family" (D. Lauber and F. Bangs. Zoning for Family and Group Facilities, American Society of Planning Officials Report #300, Chicago, Illinois, 1974).

INDIVIDUALIZED PLACEMENTS

"This service delivery model consists of small units that are almost always physically and socially integrated within the surrounding community. Services are preventive or preserving and carried out within, or in conjunction with, the client's normal living environment. Services are totally individualized; an emphasis is foremost on the clients, their reintegration into the normal home and/or the prevention of institutionalization. The environment would be typically owned, leased or rented by parents, foster parents or by the consumers themselves" (James Budde, 1975).

individual emphasis

IMPLICATIONS OF THE CONTINUUM FOR RESIDENTIAL ENVIRONMENTS

It is important for us to closely examine the implications of basing a service system on a continuum of different residential environments. This continuum, which is so widely accepted, has evolved because of a national commitment to develop less restrictive alternatives to institutions. In general, if we compare this continuum to what previously existed, when there were few alternatives to the institution, it is easy to see that we have made progress. The continuum recognized that disabled citizens have a right to the least restrictive alternative possible. For example, it is probably true that having your needs met by living in a group home in the community is better than having to live in a large segregated institution. Such an alternative is less restrictive. It tends to be more integrative and more consistent with the developmental model.

less restrictive alternatives

Positive Implications

There are, therefore, several positive implications to a continuum of residential environments.

comprehensiveness

- **The continuum of environments is so comprehensive that there are no "gaps" in residential services.** Each of these environments is said to have a "place" on the continuum. Any state or community that has a wide enough range of these environments can be assured that all of its disabled citizens have a place to live which is "matched" to their current functioning level.

mobility

- **It allows the client to move through the system as he or she grows and develops.** Initially a client is placed in a living environment which "matches" his current functioning level. As a client progresses and gains new skills he can move or "graduate" to a less restrictive setting. Without a continuum of environments this progressive movement would be impossible.

cost effective

- **A continuum is cost effective.** Proponents of the continuum argue that a continuum of residential environments is more cost effective than a service system which relies largely on the institutional model. Those clients who have progressed can move from the institution to less costly settings such as group homes or clustered apartments.

Negative Implications

The negative implications of the continuum are a result of a basic misconception:

> A disabled person must have his needs met by placement in a special and usually "segregated" environment.

It is true that there have been many positive developments over the last decade: the reestablishment of the constitutional rights of disabled citizens; the creation of innovative community service alternatives; a ten percent decrease in the institutional population; the vitalization of a national consumer advocacy movement. However, there are also some dangerous trends emerging because of our acceptance of the fundamental misconception cited above.

options

- **Different groups need different environments.** A continuum of residential environments is based on the belief that different groups or types of disabled citizens require different kinds of environments. Roles for each of these different environments are being developed. The new role of the institution is said to be that of a state or regional resource center - the living environment most appropriate for multiply handicapped children and adults. By developing a role as "the" environment for severely disabled citizens institutions are attempting to ensure their continued existence and future growth.

Group homes are emerging as "the" residential environment for moderately disabled children and adults. Such children and adults are said to need a group home environment because they cannot succeed in more integrative settings.

Nursing homes are emerging nationally as the major residential solution for individuals with special medical needs.

An indication of the pervasiveness of this approach is that it is now quite common to read of planning formulae which attach various levels of disabilities to different degrees or types of restrictive environments. This approach results in such proposals as:

> "based on our current population of 'x' number of severely handicapped individuals we will need to develop 'y' number of group homes."

- **The disabled person must "earn" his way through the system.** A major danger inherent in the continuum concept is that it places the burden of integration on the disabled person rather than on the system. For example, it is common to presume that a severely disabled person must be institutionalized until he is "ready" to move into a less restrictive community environment. Entrance and exit criteria are usually developed for each of the different living environments.

readiness

- **Cost.** The development of a comprehensive continuum of residential environments requires a tremendous expenditure of funds for purposes of renovation and capital construction. Many states are investing millions of dollars in institutional construction and renovations, under the guise of developing "more normalizing" environments.

cost

Nursing homes are mushrooming across the United States. This implies lifetime costs to keep beds filled.

Communities across the United States are funding the construction of new group homes at $150,000 to $250,000 per 8- to 12-bed group homes.

ALTERNATIVE APPROACH: An Array of Service Alternatives

The movement toward the total integration of disabled citizens into community life is at a crossroads. The development of a continuum of different environments has resulted in partial integration, partial success.

basic values

It is now necessary to focus on a further, more comprehensive implementation of our basic value system; one that will bring about a recognition of the consumers' basic human and legal rights. We must focus on the least restrictive alternative - the family for children and youth and an integrated, interdependent living situation for adults. Such a focus is not on the least restrictive **available** environment which, in some instances, may even be the institution but rather on the **absolutely** least restrictive environment - one which is a physically and socially integrated setting. Such a focus will lead us to concentrate our creative energies on the development of the array of services (not environments) necessary to enable a person, **regardless of severity of handicap,** to remain in or move to the most natural, normal setting.

An array of integrative services in graphically portrayed in Figure #2.

Such an approach should inititate a trend toward both physically and socially integrated living environments for all disabled citizens. We will be able to move from such well intentioned statements as, "A range of community services should be so complete that persons need not leave their home **communities** to receive those services necessary to meet their individual needs" to "A range of community services should be so complete that a person need not leave his **home.**"

IMPLICATIONS OF AN ARRAY OF INTEGRATIVE SUPPORT SERVICES

In analyzing this approach to service delivery and comparing it to the continuum of residential environments, several implications emerge.

legal & human rights

- **Full legal and human rights.** Such a continuum will bring about the full implementation of the concept of least restrictive alternative. By focusing on and meeting the needs of the person, the family or the community in natural environments, the least restrictive alternative will have been attained. The concept of "least restriction" will cease to be relative; rather, it will presume the natural setting to be the least restrictive. The removal of the person from the natural setting or the placement of an institutionalized person in an intermediate environment will be seen as an abridge-

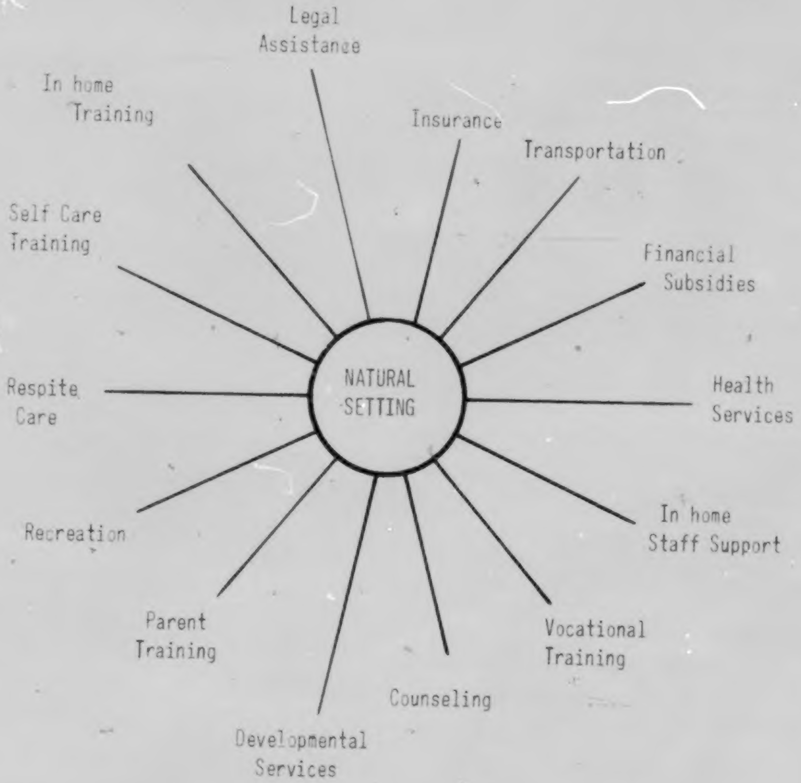

Legal Assistance
In home Training
Insurance
Transportation
Self Care Training
Financial Subsidies
NATURAL SETTING
Respite Care
Health Services
Recreation
In home Staff Support
Parent Training
Vocational Training
Counseling
Developmental Services

Figure 2

ment of the person's rights and a major compromise on the part of the system.

developmental model

- **The full recognition of the disabled person as a developmental being.** By both physically and socially integrating the person into natural residential environments, the disabled person, no matter what type or degree of handicap, will be looked upon as a developing person, capable of growth. Such developmental growth will not be equated with a continuum of environments. For example, it will not be presumed that a person's development is equated with movement through various environments; rather, developmental growth will occur in integrated settings.

normalization

- **The evolution of the principle of normalization.** The principle of normalization will be recognized as both a process and an outcome. Over the last decade normalization has helped us focus on establishing, maintaining or supporting culturally normative behaviors. But have we used means that are as culturally normative as possible? We will recognize that the person does not have to earn the right to be integrated into the community. It will be assumed that the person has the right to live in a normal environment and that the community will have to mobilize the necessary resources to accomplish this.

natural home

- **Supporting, not supplanting the natural home.** The residential assumption, referred to earlier, will be critically questioned. The first response to serving a disabled person will not be to assume "You need a group home" but rather, "How can we help you remain in your natural environment?" We will look upon supporting the person in his natural environment. This means that a wide range of services, a creative array of service options, must be developed and individualized for each client.

integration

- **Integration is the responsibility of the service system not the client.** If we are dedicated to the support of the person in his home and the development of the kinds of services to keep him there, then it will be necessary to understand that integration of the person depends more on the type and quality of the system (services) rather than on the person's needs.

costs

- **Society cannot afford both a continuum of environments and an array of integrated services.** States and communities will not be able to support a full environmental continuum (including state institutions, group homes, nursing homes) and a full array of integrative services.

It will be necessary to reverse the current funding patterns which provide only a small percentage of available funds for the support of in-home supportive services.

BARRIERS

There are a number of significant barriers to the effective mobilization of resources to meet the residential needs of disabled citizens in integrated settings. All of these barriers tend to reinforce the existence of restrictive environments and prohibit integration.

- The Federal Government, while providing 91 separate programs related to retarded citizens (PCMR, 1976), has failed to unify these programs into a force that results in quality service delivery. Often one federal thrust diminishes the impact of another. For example, Title XIX monies have been used to support institutions while at the same time Title XX monies are used to support the retarded citizens' return to community life.

- State and local elected officials are often caught in the middle of conflicts between various self-interest groups. There are powerful groups which lobby for the interest of separate programs, programs which often have conflicts of interest.

- Very few "hard" facts are known about costs and cost benefits. Cost figures are generally so nebulous that they have little impact on decision makers.

- Quite often consumer advocacy groups are divided in their efforts. For example, one state Association for Retarded Citizens is supporting a massive construction plan for the state's institutional system while the local associations are planning to return all their institutionalized citizens to their home communities.

- There has been little systematization of the major factors which make up a comprehensive integrative community service system. The typical community service program with its group homes, sheltered workshops and developmental centers does not represent a comprehensive, continuous service delivery system. Service alternatives have emerged in a haphazard fashion rather than a step-by-step, planned effort to develop integrative alternatives.

- Even in those communities where services are beginning to focus on supporting the person in his natural environment little is known about managing such a dispersed service system while maintaining quality of services. For example, a community which plans to integrate all disabled citizens is hard pressed to develop an effective management system to control such a dispersed service system. What population base is necessary to support such a system? Who monitors quality? How is it monitored? How can the myriad of federal, state and local funding sources be combined to provide the solid, enduring funding base which has characterized our institutional system?

- As we stated before, the major barrier lies in our conceptual approach to program development. It seems that some people literally cannot conceive of severely, multihandicapped individuals living, working and going to school in normal settings.

This type of conceptual barrier initially delayed the development of community programs. Some people could not accept the proposal that severely handicapped individuals could live in noninstitutional settings. We have largely overcome this attitude by proving that community alternatives can meet the needs of retarded citizens.

Now we have a more difficult and, in a sense, more important challenge. We must convince parents, advocates and professionals that mentally retarded citizens have a basic right to the opportunity for full involvement in their community. It is not a question of whether this approach will be successful. We must make it work; it must be successful.

CONCLUSIONS

restrictive environments

Restrictive environments, whether the state institution or a large group home, have no role to play in the lives of disabled citizens. Residential alternatives that are now valued so highly in communities across the United States will have to be radically altered to allow for full integration of disabled citizens. Group homes, for example, will not be seen as permanent residences but rathere as staging points for integration.

natural environments

We realize that our service systems have not progressed to the point that there is no longer a need for a continuum of residential environments. We have not yet developed the supportive mechanisms and services necessary to support all disabled individuals in natural environments. However, if we are to develop such supports and services we must begin now - to plan; to develop funding sources; and educate the public.

> "Can we foresee a day when there will be no need for our residential services? Hopefully, someday it will be

assumed that mental retardation is not the handicap that precipitates the need for residential services. It is much too often the end product of our failure to support the family or open the doors to existing resources." Ed Skarnulis. Residential Services: Support, Not Supplant, the Natural Home, 1975.

Deinstitutionalization

FRED J. KRAUSE

Why is it so difficult for people to admit error in judgment? And we committed serious error in creating large public institutions to house the mentally retarded as early as the 1850s.

We are here today because we still haven't corrected what has become a major social problem: because of the age-old social practice of rejecting the mentally retarded, not just by putting them out of the way in big buildings, but for decades partitioning them off wherever they are; by crossing them off because our society in general has been not willing to be involved with retarded persons.

We in this room may think we are different or more creative. I have heard the expression that we must continue our persistence in seeking "mainstream living quarters for them" or our rejection of "traditional approaches," sets us apart from the superintendents who run the large medical institutions. But does it? Are we doing what we would like to think we are doing? Whose problems are we solving when we move retarded persons out of structures we abhor and into structures we prefer? Are we fair in our abhorrence? Are we rational in our preference? Do the people we relocate share our feelings?

mainstream

During this conference we will examine the various models of residences for retarded citizens. I propose that you must be very mindful of the critical issues and management problems in the endeavor you are espousing. Years of study, lifetimes of professional effort have produced only partial solutions to the problems surrounding institutionalization and alternatives to it.

partial solutions

A beginning would be in closing the separation between parents and professionals in the development of policy planning and operation of residential programs. Our starting point must be the existing repositories of experience and knowledge.

institutional reduction

In 1971 a national goal was announced by the President's Committee on Mental Retardation to reduce the institutional population by at least one-third by 1980. Now let's examine progress. In 1972 this population was 181,035; in 1976 it is reported to be 153,584, a reduction of 20,351, or 16 percent (see Figure 1). Dr. Richard Scheerenberger was commissioned by PCMR to survey the trends in public residential facilities.

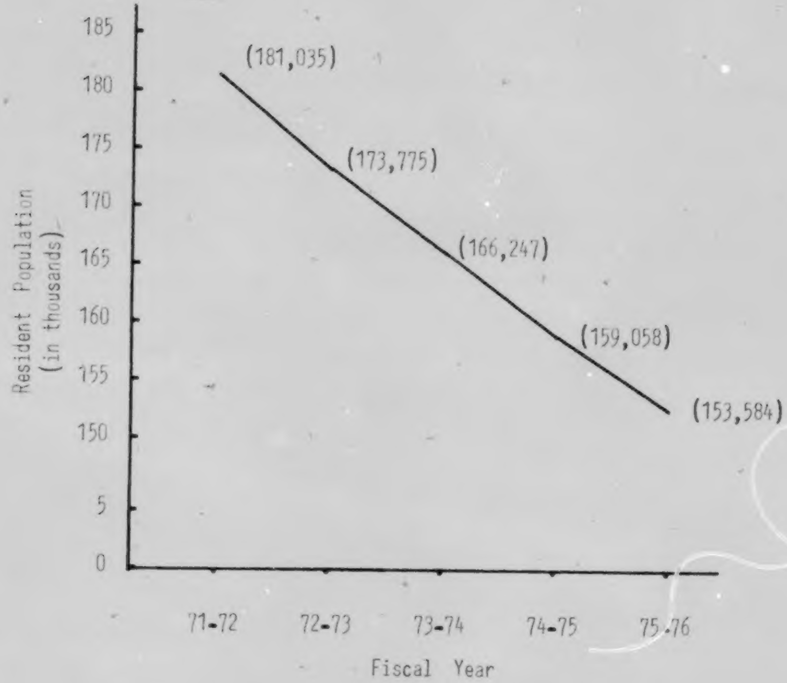


Figure 1. Average Daily Population of 237 PRF's: FY 71-72 Through FY 75-76

The results of the study are shown in Figure 2 (page 30). There are 237 operational facilities for the mentally retarded. Twenty-one (8.9 percent) opened between 1850 and 1899 and another 64 (27.0 percent) accepted their first resident between 1900 and 1949. Thus, the majority of public residential facilities have been established over the past 26 years. Scheerenberger's data indicate that while progress is evident in both deinstitutionalization and institutional reform, much remains to be accomplished.

indicators

With regard to deinstitutionalization, the number of retarded persons requiring residential services continues to decrease, but at a slower rate than in former years. Other positive indicators include a reduced admission and readmission rate plus increased projected placement statistics for the forthcoming year.

population trends

While the resident population continues a gradual trend toward becoming both older and more seriously affected, many less affected persons are still being served. Admission, readmission and waiting list data also include a relatively high percentage of moderately and mildly retarded persons of all ages. Too many individuals returned to the community appear to be failing because of inadequate local services. Taken collectively, data clearly suggest that comprehensive community programs still need to be developed in many places throughout the country.

reform

Residential reform has been evident. This was reflected in the general reduction in rated bed capacity, better staff-resident ratios, increased enrollment of the severely and profoundly retarded in various programs, extended programming for adults, increased parental participation and individualized program plans.

deficits in programming

On the less positive side, and in spite of increased staffing and programming, very few public residential facilities can satisfy either the 249.12 or 249.13 regulations associated with Title XIX, and relatively few have been accredited by the JCAH Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons. Continued deficits in resident programming, the apparent need for special services for emotionally disturbed individuals and the relatively high percentage of retarded persons maintained in locked wards during the day all indicate that substantial residential reform is still required. Also, the relatively common practice of retaining retarded persons in public residential facilities after they are capable of leaving needs to be reexamined.

As indicated previously, gradual gains are being made with respect to both deinstitutionalization and residential reform. Governments, both state and federal, have increased substantially their respective contributions to meeting the needs of mentally retarded citizens. A continuation

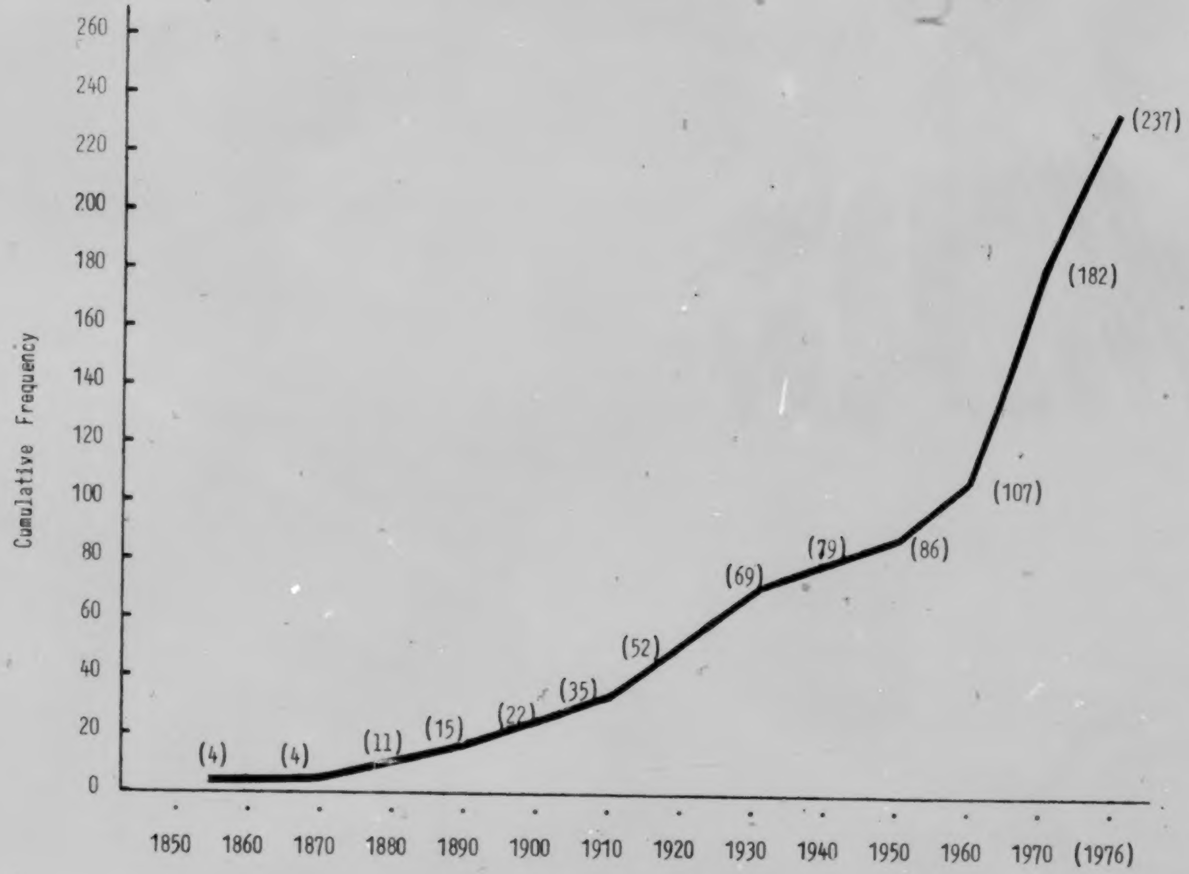


Figure 2. Growth of Public Residential Facilities in the United States

of this concern and effort will be required before each retarded person can live a self-fulfilling life in the least restrictive environment.

The goal of deinstitutionalization can be achieved through three inter-related processes:

goals

- **The development of a comprehensive array of residential and supportive services in the local community.** Offering such alternative services will make it possible to reduce the number of admissions to institutions as well as support those retarded individuals who are returned from institutions to community residences.

- **Acceleration in the transfer of retarded residents from institutions to the community.** This would represent the major number of those persons whose community care reduces the institutional populations. Acceleration of the deinstitutionalization process can be achieved through such activities as:

  A. Training of staff at public institutions to encourage residents to return to the community and to provide preparatory habilitation services;

  B. Selection of residents and their preparation through special training programs for their release;

  C. Preparation of families for the return of their retarded members;

  D. Provision of responsible agents to negotiate the change of residence; and

  E. A follow-along program to give support to each retarded individual during his transition to, and stabilization in, the community.

- **Development of a responsive community.** Creating a tolerant, accepting and supportive community environment will make it possible for the deinstitutionalized retarded person to survive and progress in the community and will reduce the demand for re-admission to public institutions.

CAN A COMMUNITY RESIDENCE BECOME AN INSTITUTION?

David Sokoloff, an architect who has designed many facilities for retarded persons, says a community residential project often becomes an ego trip for the people involved. He points out that "creating a building is a very problems of isolation

intoxicating experience, for the result is a tangible and lasting expression of creativity." He also points out that buildings frequently fail in their purpose. In the words of Ann Shearer, another long-time observer, "Anyone who has spent time in visiting new community establishments will have recognized, with something like a feeling of terror, that the abuses of the old system can be reproduced exactly and perhaps even more cruelly in the relative isolation of a community setting."

Attention is wrongly focused on the size and location of buildings in which retarded persons live. What matters more is the relationship between the provider and the client.

When a community residence for retarded persons is established, it may be an institution in the process of being created. It may be called a home and it may be regarded as such by the people who live there. But it may be managed as an institution. Group homes, supervised apartments and even foster homes employ labor, purchase goods and services, apply for and receive program funds and in growing numbers of cases these smaller facilities are mismanaged and lack individualized program plans for their residents.

personnel

Like health care institutions, community residences have staffing problems. Low salaries, long hours and lack of privacy -- especially for live-in personnel -- are facts you cannot eradicate, though there are ways of compensating for them. Personnel need emotional and educational support, as well as outside assistance from volunteers and paid workers.

ECONOMIC PROBLEMS

Self-sustaining solvency is more likely to be a goal than a reality in a community residence for retarded persons. If you plan to pay for all the necessary services, you probably are headed for trouble. Jean Vanier, founder of L'Arche, states flatly, "Our houses can only live through gratuity. If tomorrow everybody went on standard rates for house and salaries, our houses would collapse."

employment

Even under the best of circumstances it is unlikely that severely retarded persons will be able to contribute much to their own upkeep by working. It has been found that in many communities jobs are hard to find or are not available. Many retarded persons now living in community facilities could work and want to work but cannot find employment. And when they do find openings, the wages are low.

Government support of retarded children and adults in community residential programs is presently too uncertain to be very helpful. Inequities and absurdities abound. A retarded person entitled to support in an institution may not be entitled to the same support if moved into the surrounding community.

These economic disincentives are irrational and unintentional, but they have not yet been corrected. And we are on thin ice if we argue that it is cheaper to keep retarded persons in community facilities than in big state institutions. In the first place, sometimes it is not cheaper. Better perhaps, but not cheaper, dollar for dollar. In the second place, it is hard to tell exactly how much it costs to keep people in institutions. Federal payments for institutionalization sometimes go into a general fund at the state level and are spread around so that it is impossible to be sure money intended for retarded persons actually is spent to support the so-called beneficiaries.

Everyone would like to believe that community placement of retarded persons is a sound business proposition, that community residences can be self-supporting, that goods and services can be purchased without reliance on cumbersome public funding and meddlesome bureaucracies. This is not currently a reality.

Once a retarded person is "released" from a public institution and placed in a less structured setting lines of responsibility blur. Who ultimately is responsible for providing needed services? The institution? The community? The retarded person's family? When the crunch comes, who decides whether or not community placement is feasible, whether or not a specific individual should be sent back to an institution?

responsibility

COMMUNITY RESISTANCE

Receptive communities are hard to find. Group residences for retarded individuals usually are tax-exempt, and neighbors may fear that erosion of the community tax base will result in higher taxes and fewer services. Unfortunately, areas that make it easy to establish residences for disabled persons may experience an unsettling influx of facilities. For example, in Montgomery County, Maryland, where I live, a liberal policy on establishment of group homes for retarded people is in danger because neighboring counties and cities have taken advantage of the lack of necessity for zoning exceptions. Group homes for various social problems are springing up all over, and the citizens are beginning to worry. The County Council is now considering legislation to make group homes get zoning exceptions before opening in residential areas.

zoning
exceptions

Aside from economic considerations, it cannot be denied, and must not be forgotten, that many people are subliminally afraid of the handicapped.

prejudice

When these people say they are worried about property values in the neighborhood or the tax base in the community, what they mean is they fear mental deficiency, they are repulsed by disability, they feel threatened by the proximity of retarded persons. All of us must exert ourselves to counteract this sort of prejudice.

WHOSE HOME IS IT TO BE?

A lot has been written and said about admissions standards for community residences, but there are few usable criteria. We must develop mental and physical function scales that are reasonably accurate in forecasting ease or difficulty of adjustment to community living. These predictive tools are necessary to plan supportive services. They need not become levers for exclusion of certain retarded people.

client needs

Too often community residence planners gloss over the need to decide specifically and carefully what type of person will be living in the facility everyone is dreaming about. In committee meetings people tend to assume that the residence they are discussing will be inhabited by persons who are fairly mildly disabled, capable at least in some ways. Everyone knows some retarded people are much more handicapped than others. But no one wants to tell Mr. and Mrs. Smith, both of whom have been active on the committee, that possibly their child is too young or too disabled to, at this time, be placed in the residence they opened.

When the really tough problems are mentioned -- for example, physical impairment and severe behavioral problems such as head-banging, violent emotional outbursts, biting and sexual acting out -- the planners say..."Well, this home will not be able to manage that child." Often no one is too clear on exactly who will live there, so the unspoken assumption prevails. The facility is built for "medium" cases, and when the ambulatory handicapped individual has come and gone, nothing can be done to accommodate more severely retarded, non-ambulatory human beings.

THE MANY GOOD THINGS ABOUT COMMUNITY PLACEMENT

client independence

It has been shown that community placement does accomplish many of of the things its supporters say it will. A recent study by Richard Scheerenberger of foster homes, group homes and other community facilities for the retarded showed the people living in them did indeed prefer the community to the institutions they had left behind. Even the more severely retarded and multiply handicapped individuals were adjusting well. Even the older adults were showing measurable progress toward independence.

But some problems were obvious. For example, work opportunities were few and at a low level. Day programming was sometimes inadequate. Access to public transportation was sometimes nonexistent. And--homelike atmosphere or not--conformity was required in that residents participated in activities collectively, went to bed and ate at fixed hours and were forced to "fit" in a variety of other ways as well.

work opportunities

Gail O'Connor's nationwide study of homes for developmentally disabled persons, including the retarded, showed that community facilities were better than many had feared to find if they looked. But the researchers emphasized the need for meticulous planning, careful program implementation and ongoing monitoring. They pointed out that the success of community placement is creating potentially dangerous pressure in favor of deinstitutionalization. Caution must not be thrown to the winds, for retarded clients are the ones who will suffer.

THEY CALL IT NORMALIZATION

In the words of N. E. Bank-Mikkelsen, a famous Scandinavian proponent, normalization has become a new "ism." Without understanding the intentions and implications of the original concept, civic leaders of all sorts, parents of retarded persons, politicians and even specialists in mental retardation jump up willy-nilly and go out to do good in the name of "normalization." The word is in vogue. The idea is dogma. To question normalization is to provoke accusations of heresy.

Yet normalization is mistaken for normality. This is no excuse for the knee-jerk reaction against examining old habits and cherished beliefs in terms of the goal of normalization. But please -- consider the original concept. Consider existing misconceptions.

COMMENTS ON DATA AND TRENDS

In Dr. Richard Scheerenberger's recent trends study done for PCMR, he comments that the data indicate that while progress is evident in both areas of deinstitutionalization and institutional reform, much remains to be accomplished.

With regard to institutionalization, the number of retarded persons requiring residential services continues to decrease, but at a slower rate than in former years. Other positive indicators include a reduced admission and readmission rate plus increased projected placement statistics for the coming year.

admissions

While institutional populations continue a gradual trend toward becoming both older and more seriously affected, many less affected persons

community
programs

(moderately retarded to normal) are still being served. Admission, readmission and waiting list data also include a relatively high percentage of moderately and mildly retarded persons of all ages. Too many individuals who have been returned to the community appear to be failing because of inadequate local services. Taken collectively, these data clearly suggest that comprehensive community programs still need to be developed in many places throughout the country.

Residential reform was evident. This was reflected in the general reduction in rated bed capacity, better staff-resident ratios, increased enrollment of severely and profoundly retarded persons in various programs, extended programming for adults, increased parental participation and individualized program plans.

CONCLUSION

While I may have certain concerns about the progress of group living in the community, I believe that every retarded child and adult who can should live in an ordinary residence in an ordinary community, with necessary help but without unnecessary restrictions.

individuality

In fact, the proper function of a residential facility -- whatever its size, whether it is a community facility or not -- is to provide a setting in which the resident can find his or her own way of relating to the external world and to himself or herself. The task before us is no more and no less than this.

We are proceeding. You are proceeding. Miller and Gwynne have noted that as enthusiasm builds, the great danger is that we will impose our preferences on persons who do not share them, on persons with whom we do not fully empathize, though we may love them dearly.

We must watch ourselves closely and ask ourselves questions. When we create community residences and put retarded people in them, do we serve the mentally retarded or do we really serve ourselves? Why do we frown so omnisciently on life apart from the so-called mainstream? According to what standards do we downgrade human existence in limited circumstances?

ambivalent
attitudes

We must confront our ambivalences, examine discrepancies between professed attitudes and behavior and try to distinguish reason from rationalization. This is difficult, but those of us who have responsibility for the lives of others must try.

Let's not expect a pardon from our responsibility.

Funding Resources

SUSAN WEISS MANES

Significant resources exist at the federal level to support the ongoing operation - and to a lesser extent, construction and start-up costs - of group homes and other community residences. Nevertheless, there is a widespread conviction that these resources - alone or in combination with state and local funds - are inadequate.

The barriers to effective use of these federal funds are diverse.

- Some programs are under-funded.
- Others do not have a long-standing commitment to mental retardation and are reluctant to become involved in something they understand poorly, if at all.
- There are gaps in coverage - construction funds and start-up support are much harder to come by than operational funds, for example.
- Finally, and most significantly, the various federal programs must be pieced together into a cohesive funding package - a formidable undertaking, given differing program managers, operating procedures and eligibility standards.

I am going to outline the major federal programs which fund either start-up or operational costs in community residences and at the same time identify any barriers which exist to effective utilization of these programs - not to discourage you, but to help you understand more fully how these programs work.

Let me note at the outset that I have been asked to limit myself to reviewing those federal programs which can be used to support start-up and operational costs in community residences. This discussion does not, therefore, include an analysis of federal programs available to fund the non-facility-based aspects of a community-based service system - such as transportation, vocational services, education, advocacy and so on. Obviously, these services - coordinated, part of an organized system, with a clear focal point of responsibility - are every bit as vital as the residential aspects of developing community-based services.

With that introduction, let's begin with the federal cash assistance programs, which can often form the cornerstone of financing room and board costs in a community residence, since the individual resident can use his or her monthly check to pay a pro rata share of these operational costs.

There are two major federal income maintenance programs - Supplemental Security Income and Disability Insurance.

SUPPLEMENTAL SECURITY INCOME

1. Program Description:

monthly benefits

As I think most of you know, the Supplemental Security Income program is a federal cash assistance program which provides monthly cash benefits of up to $167 to low-income aged, blind and disabled persons. To be eligible a person must have limited assets and little or no earned or unearned income (certain assets and income are disregarded, however). To qualify as disabled, a mentally retarded person must be unable to engage in "substantial gainful employment" as a result of a medically determinable condition.

Persons eligible for SSI may use their monthly checks to support themselves in community residences. A number of states supplement the federal payment, and this supplement may also be used by a recipient to pay his room, board, personal and other expenses.

2. Issues and Problems:

statutory provisions

A. There have been a number of statutory provisions which limited the eligibility of persons in certain community residences. Until very recently people living in publicly operated institutions were ineligible for SSI and the term "institution" is defined so broadly that it includes group homes. Second, governmental subsidies to persons in private group residences were considered income to the resident, if used to pay for room and board, and acted to reduce the SSI payment by up to one-third.

Recently enacted legislation, however, has eliminated these problems (P.L. 94-566). This legislation, known as the Keys Group Home Amendment, was signed into law on October 20 of this year -- and because of the recentness of enactment no implementing regulations will be published for some time.

The statutory language, however, makes persons living in publicly-operated or sponsored community residences for 16 or fewer persons eligible for SSI benefits on the same basis as persons living in private facilities and provides that cash or in-kind benefits provided to or on behalf of SSI recipients by state or local governments, if based on need, will not be counted as income.

keys amendment

In addition, the Keys Amendment repeals Section 1616(e) of the Social Security Act, an extremely complex provision which was designed to discourage states from financing substandard nursing home care through residents' SSI payments, thus evading Medicaid standards. It did this by requiring a dollar-for-dollar reduction in the federal SSI payment by the amount of any state supplemental payment used to purchase medical or remedial care of a nature which could be financed through the Medicaid program. Section 1616(e) was never implemented, however, because of the complexity of its statutory language and the Social Security Administration's inability to define the difference between a substandard Medicaid facility and a legitimate social care institution. Many persons both inside and outside HEW felt that the statutory language of Section 1616(e) would have required all community residences providing more than room, board and laundry to meet the Medicaid intermediate care facility standards.

standards

The Keys Amendment provides an alternative approach to the issue of substandard facilities by requiring states (effective October 1, 1977) to "establish, maintain and insure the enforcement of standards" for the whole spectrum of non-medical residential settings in which SSI recipients live or are "likely" to live. The standards must be appropriate to the needs of the residents and the character of the facility involved and must cover at least admission policies, safety, sanitation and the protection of civil rights. The state must designate one or more state or local authorities to be responsible for the development and enforcement of these standards.

States must annually make available for public review, as part of the Title XX annual services plan, a summary of the standards. In addition, the state must provide to any interested individual, on request, the following:

- A copy of the actual standards;
- A description of the system for their enforcement;
- A list of any waivers of the standards; and
- A list of any violations of the standards.

SSI reductions

SSI recipients living in facilities which are not approved as meeting the standards will be subject to a dollar-for-dollar reduction in their federal SSI payment by the amount of any state supplementary payment which is used to pay for medical or remedial care provided by substandard facilities.

B. A significant problem with using SSI payments to meet room and board costs is that the basic federal payment - $167 a month - is often inadequate to meet actual costs and must be supplemented by the state or some other source. A number of states supplement the federal payment only marginally, however, and some not at all.

state supplement

This picture has been improved to some extent by recently enacted legislation (P. L. 94-585) which requires states already supplementing the federal payment to continue that supplementation on a permanent basis. This will prevent states from reducing their own supplementation levels every time that the federal payment is increased through the automatic cost of living escalator.

C. Another difficulty in using the SSI program is that eligibility is limited to those persons whose mental retardation disables them to the point that they are unable to earn substantial wages or engage in "substantial gainful activity" - a term which the Social Security Administration continues to interpret and re-interpret, but which remains a matter of contention. The Social Security Administration has recently announced that it intends a major revision of its definition of substantial gainful activity. I invite all of you who may have experienced difficulty with the existing definition to share your comments with the Social Security Administration or our office.

gainful activity

DISABILITY INSURANCE: TITLE II OF THE SOCIAL SECURITY ACT

Program Description:

The second major federal income maintenance program is disability insurance. Disability insurance payments, like SSI, can provide beneficiaries with a source of income to support themselves in a community residence. Mentally retarded adults are eligible to receive monthly disability insurance payments through the Social Security system if:

- They are over age 18; and
- They have a disability which originated in childhood; and
- The disability results in an inability to perform substantial gainful employment; and
- They are covered for Social Security payments on the record of a retired, deceased or disabled parent; or
- They are covered for Social Security payments on the basis of their own employment history.

The most serious problem with disability insurance is that coverage is limited to persons whose parents are themselves retired, deceased or disabled and covered under the Social Security system.

THE HOUSING AND COMMUNITY DEVELOPMENT ACT (P.L. 93-383) SECTION 8 HOUSING ASSISTANCE PAYMENTS

1. Program Description:

Another federal program which can be used to partially meet operating costs is the Section 8 Housing Assistance Payments program authorized under the Housing and Community Development Act and administered by HUD.

The Section 8 program authorizes HUD to provide rent subsidies on behalf of eligible low-income persons occupying new, substantially rehabilitated or existing rental housing. Subsidies are paid through assistance payments contracts with owners (who may be private owners, cooperatives or public housing agencies). Eligible persons are those who, at the time of initial renting of units, have total annual family incomes not in excess of 80% of area median income; but the Secretary of HUD may establish higher or lower income ceilings if she finds such variations necessary because of prevailing levels of construction costs, unusually high or low family income or other factors.

rent subsidies

The amount of assistance provided with respect to a unit will be an amount equal to the difference between the established maximum rent for the unit and the occupant's required contribution to rent. Aided persons will be required to contribute not less than 15 or more than 25 percent of their total income to rent, with the Secretary of HUD authorized to establish required contribution levels (taking into consideration the extent of medical or other unusual expenses incurred by the persons). For persons with exceptional medical or other expenses, the required contribution level is statutorily fixed at 15% of total income. Assistance is specifically made

contribution levels

available for congregate living arrangements, such as group homes, cooperatives, and in Section 202 projects for elderly and handicapped persons.

property standards

To be approved for participation in the program, housing must meet certain requirements. These include compliance with HUD's minimum property standards for congregate housing where appropriate; accessibility to social, recreational, educational, commercial and health facilities; and compliance with the local housing assistance plan required under the community development program authorized by Title I of the Housing and Community Development Act of 1974.

block grants

This latter requirement is a very important one to understand. The Community Development Block Grant program, authorized under Title I of the Housing and Community Development Act, provides funds to states and units of general local government for a variety of community development activities. Consistent with the block grant approach, recipient governments are given very broad flexibility in deciding how to use these funds for the diverse number of activities which are eligible for funding under the statute.

The Community Development Block Grant is not a housing program and cannot generally be used to pay for housing. Despite this, the Block Grant cannot be left out of any discussions of housing for mentally retarded persons. This is because local communities, in order to receive Community Development funds, are required to submit a "housing assistance plan," which surveys the housing needs of the community and specifies annual goals for meeting these needs. By law, the plan must specifically address itself to the housing needs of handicapped persons.

The purpose of requiring the housing assistance plan as part of the Community Development application is to foster "the understanding of housing and community development activities in a coordinated and mutually supportive manner."

housing assistance plan

In considering applications for Section 8 and Section 202 funds, HUD is generally bound by the Housing Assistance Plan (HAP) and the degree to which Section 8 or 202 applications are consistent with the HAP.

Let me return to the Section 8 rent subsidy.

In the case of newly constructed or rehabilitated housing, application for Section 8 payments is made by owners, who must submit development proposals in response to a published invitation for proposals by the HUD area office. If both the preliminary and final proposals are acceptable to HUD, HUD will enter into an agreement that upon completion of the project it will enter into a Housing Assistance Payments Contract with the owner for a specified term. Under this contract, HUD will make housing assistance payments with respect to units occupied by eligible families.

The process of applying for Section 8 assistance in existing housing is different. Under this program an individual who is determined eligible by the Public Housing Agency (PHA) will be given a Certificate of Family Participation. The individual may then seek a suitable unit anywhere within the operating jurisdiction of the PHA. If the owner is willing to lease a unit, and the unit is determined to be in decent, safe and sanitary condition, and if the gross rent is within the HUD established fair market rent for existing housing, a lease may be executed between the owner and the individual and a Housing Assistance Payments Contract will be executed between the PHA and the owner. This contract will assure a monthly payment to the owner in an amount sufficient to make up the difference between the rent payable by the individual and the contract rent to the owner.

public housing agency

Section 8 payments can also be used by state Housing Finance and Development Agencies (HFAs), now present in 32 states. Most HFAs provide below-market rate financing to private developers of low- and moderate-income housing. The regulations permit qualified agencies to receive "set-asides" - earmarkings of Section 8 funds which the HFA can allocate generally according to its own housing program. The Section 8 subsidy payments with respect to an HFA financed project are computed and disbursed in the same manner as for the basic program.

HFA projects

2. Issues and Problems:

A. Using Section 8 subsidies is difficult but not impossible. However, the problems with Section 8 are legion. HUD's lack of familiarity with, or commitment to, small group housing for mentally retarded persons has created serious attitudinal barriers to using Section 8 funds. These attitudes, while changing for the better, have responded only slowly to educational efforts on the part of outside groups.

B. The administrative complexities of the program constitute formidable barriers to the most sophisticated potential sponsors and actively discourage less experienced groups from seeking Section 8 funding. This is particularly true with the Section 8 program as it operates in newly constructed housing. This being the case, you would be well advised to approach your state Housing and Finance Agency to serve as a broker between you and HUD and perhaps to provide a seed grant or low-interest mortgage, if you are interested in construction. HFAs have a history

seed grants

of being more interested in "special housing" than local housing authorities.

C. The minimum property standards applied to Section 8 housing are not appropriate to normalized living. HUD has committed itself to rewriting these standards as they apply to group homes but has not done so to date. Draft proposed rule-making is now undergoing final clearance within HUD.

fair
market
rents

D. The Section 8 program, by itself, cannot support the cost of construction. Even where some other financing vehicle is obtained to support construction costs (from a state HFA, for example), Section 8 Fair Market Rents usually force a sponsor to build housing with a minimum of 12 residents.

advocacy

E. The requirement that Section 8 housing be consistent with the local community's Housing Assistance Plan (which must be submitted as part of the Community Development application) means that sponsors must convince their communities to include small group housing for mentally retarded persons in their plan. Although communities are required by law to publicize their plan and solicit citizen comments, many ARCs and other advocates have not involved themselves in the development of the plan or have participated only in the most limited way. In still other cases, concerted efforts have been made to influence the Housing Assistance Plan but have been rebuffed or ignored by the responsible local officials. The end result in both cases has been that most Housing Assistance Plans give short shrift to the housing needs of mentally retarded persons.

SECTION 202 LOAN PROJECTS FOR THE ELDERLY AND HANDICAPPED

1. Program Description:

construction
loans

Another HUD program is the Section 202 Loan Program for the Elderly and Handicapped. Under the Section 202 program, HUD is authorized to make direct construction loans to non-profit sponsors of housing for elderly and handicapped persons. The definition of "handicapped" specifically includes developmentally disabled persons.

Loans are made at the Treasury borrowing rate, plus an allowance for administrative costs. A total of $3.2 billion is authorized under the program. Appropriations for FY 1976 were $750 million and are expected to exceed that amount in FY 1977.

Applications for Section 202 support are made in response to a HUD-initiated Request for Reservations of Loan Funds. Rating criteria developed by HUD stress experience in the construction and management of housing and the long-term financial situation of the applicant agency. By regulation HUD has required Section 202 sponsors to participate in the Section 8 program, thus imposing tenant income eligibility standards of the Section 8 program onto the Section 202 program.

2. Issues and Problems:

A. HUD's requirement that Section 202 sponsors also obtain Section 8 operating subsidies has burdened the Section 202 program with all of the problems the Section 8 program currently labors under.

stability

B. HUD's criteria for evaluating 202 applications stress past experiences in operating housing programs and long-term financial stability - factors which operate to eliminate many applications for small group housing for mentally retarded persons.

C. HUD is reluctant to fund small-scale applications, with the result that those few projects funded for mentally retarded persons to date have tended to be clusters of community residences on one "campus" or large facilities in the community which differ significantly in size and physical appearance from the typical family home.

D. The competition for Section 202 funds is very intense. This problem will be somewhat ameliorated with the expected increase in appropriation levels, but will nevertheless continue to limit the use of Section 202.

SOCIAL SERVICES: TITLE XX OF THE SOCIAL SECURITY ACT

1. Program Description:

The Title XX program is an excellent vehicle for supporting the service aspects of running a group home: program planning, staff support and so forth. In addition, it can pay room and board costs up to six months, under certain conditions.

The Title XX program authorizes the Federal Government to share in the costs of providing social services to eligible low-income persons. Under Title XX there are five fundamental goals towards which services must be aimed, including "preventing or reducing the more intensive forms of institutionalization by providing for community-based care, home-based care, or other forms of less intensive care..."

goals

States have very great discretion in choosing which services to fund under their Title XX allotment, providing that the service in question falls under one of the five goals established by the legislation.

The Federal Government will pay 75% of the costs of services (up to the state's allocation under the $2.5 billion ceiling), except in the case of family planning services, for which the federal share is set at 90%.

free services

Services may be provided free of cost to anyone whose gross income, adjusted for family size, falls below 80% of the state's median income level at the state's option. A sliding payment scale is established for persons with gross adjusted income between the 80% median level and 115% of the median.

Some services are excluded from payment under Title XX, including:

- More than six consecutive months of room and board;
- Medical or remedial care, other than family planning services, which can be paid for under Medicaid or Medicare;
- Services provided directly by "medical institutions" (hospitals, skilled nursing or intermediate care facilities) or by prisons or foster homes to their inmates or to their residents (in-reach services to medical institutions are not excluded. Also, services provided by group homes which are not "medical" - intermediate or skilled nursing facilities - would be eligible for support); and
- Capital expenditures.

excluded services

advocacy

States are required to make public their plans for using their social services monies. Since states are given great freedom in using these funds, effective advocacy at the state level is required to assure that mentally retarded persons are adequately served.

state agency

If the state social services program includes services to persons in institutions, the state is required to designate or establish a state agency for developing and maintaining standards. The standards must cover at least: admission policies, safety, sanitation and protection of civil rights.

2. Issues and Problems:

A. The $2.5 billion ceiling on federal social services expenditures has created a very intense competition for Title XX funds. Most states have either reached their ceiling or are very close to doing so. As a result, funds for new programs can come only if old programs are cut back or eliminated. Some states are experiencing reductions in programs for retarded persons.

B. Decisions on what activities to fund with its Title XX allotment rest with the state. These decisions are reflected in annual Title XX state plans, which must be available for public review and comment before being finalized. Effective use of Title XX thus requires effective advocacy at the state level by interested consumer groups.

MEDICAID: TITLE XIX OF THE SOCIAL SECURITY ACT

1. Program Description:

Under the Medicaid program the Federal Government will share with states in the cost of providing medical and other health-related services to eligible low-income persons who meet certain categorical requirements (membership in a one-parent family, SSI eligibility, etc.). Matching rates under the Medicaid program vary from state to state, but the federal share is never less than 50% and, in some states, is as high as 83%. Federal funds under Medicaid are not subject to appropriations - they are open-ended.

shared costs

Some 38 states cover intermediate care facility services for mentally retarded persons in their state Medicaid plan. This means that the states make vendor payments to public and private facilities to reimburse them for the cost of residential services to eligible mentally retarded residents.

The statutory definition of an ICF - as well as HEW's early administration of the program - clearly focuses on larger institutions. Nevertheless, a handful of states have used the ICF program to support group homes for persons who require considerable habilitation and, in some cases, for persons who have relatively highly developed skills.

group homes

2. Issues and Problems:

HEW's ICF/MR regulations, while they permit some differences in application for facilities with 15 or fewer residents, are not generally appropriate to the service delivery style of the typical group home. HEW is currently participating in a one-year experiment in Minnesota using modified ICF/MR regulations in group homes and has expressed an interest in modifying the existing regulations on a national basis for at least some types of group homes. However, the question of when a group home should be an ICF and when it should be financed through some other system remains the subject of vigorous debate inside and outside the government.

service style

DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT (P. L. 91-517 as amended by P. L. 94-103)

1. Program Description:

Under the Developmental Disabilities program, formula grants to the states may be used for planning, administration, services and construction of facilities for developmentally disabled persons.

In many states Developmental Disabilities funds have been used as seed money grants to individual group homes and other community residences.

2. Issues and Problems:

The very limited funding level of the Developmental Disabilities program, coupled with intense competition for DD support, creates obvious limitations on the role of the DD program in supporting group homes.

Funding Strategies

RITA CHARRON

We must continuously strive to develop new funding resources and, at the same time, make full use of those resources we already have. Existing resources require considerable maneuvering and management if they are to be applicable in supporting a continuum of residential services.

Knowledge of federal and state funding systems, the regulations for their use and necessary interfacing with other programs is absolutely essential if we are to design the best possible community living opportunities for retarded people. There is no substitute for a thorough understanding of federal, state and local funding procedures for service delivery systems.

Often a state will discover one convenient method for funding a particular type of residential care. Then, all efforts are expended to make that one funding process support the total service needs. As a consequence, all clients are forced to fit the regulations of this one type of program regardless of individual needs. This becomes another form of institutionalization.

single
approach

To begin our discussion of funding strategies let us look at a sample continuum of residential environments. These examples are not intended to be all inclusive, but they will give us a workable community residential plan to start with.

The types of community housing, methods of funding start-up of the housing, methods of financing building or renovating and procedures for operating are shown in Figure 1 on page

RESIDENTIAL CONTINUUM

COMMUNITY HOUSING	START UP	BUILDING DEVELOPMENT	SERVICES OPERATIONS
Own Home			SSI - DI St. & Co. MR $ Title XX Title XIX
Foster Home	D. D. Title XX		SSI - DI St. & Co. MR $ Title XX Title XIX
Group Home	Local HUD Sec. 8 HUD Sec. 202 D. D. Farm Home	HUD Sec. 8 HUD Sec. 202 Local Farm Home	SSI - DI HUD Sec. 8 & 202 St. & Co. MR $ Title XX Title XIX
Apartment Supervised	Private	Private HUD Sec. 8	SSI - DI HUD Sec. 8 St. & Co. MR $ Title XX
Congregate	HUD Sec. 8 Private	Private HUD Sec. 8	SSI - DI HUD Sec. 8 St. & Co. MR $ Voc. Rehab.
ICF/MR	Private	Private HUD - Loans	Title XIX St. & Co. MR $
Skilled Nursing Home	Private	Private HUD - Loans	Title XIX St. & Co. MR $
Village	Private	HUD Sec. 8 Private	SSI - DI Client Income

Figure #1

DD = Developmental Disabilities
DI = Disability Insurance
HUD = Housing & Urban Development
ICF/MR = Intermediate Care Facility for Mentally Retarded
St. & Co. MR = State & County Mental Retardation
SSI = Supplemental Security Income
Title XIX = Medicaid
Title XX = Social Security Funds

Resources which are **available** may not always be easily **accessible.** Flexibility in the way accountability is established for community service systems will continue to be necessary. A recent survey of our states, prepared by the National Association for Retarded Citizens' Task Force on Funding, identified the various funds which states and communities are currently using to support and operate community residential systems. From these states we can learn strategies for using the available housing support programs.

accessibility

In spite of the lack of clear and well defined procedures for funding community facilities, states have independently developed a variety of effective systems. Much can be learned from reviewing the strategies used by other states. I have selected four states as examples; these are not models. They demonstrate procedures for combining federal, state and local resources into a support system for community residential environments.

Pennsylvania offers a rather complete continuum of residential services. Figure 2, (page 52) shows a wide use of different funding mechanisms. Most types of residential environments are developed by both private non-profit and profit making groups.

Pennsylvania

In Figure 3 (page 53) the support system shows direct simple lines of authority with a well defined money flow. Not all available resources are used by Pennsylvania. The private provider receives public funds to operate community homes of all types.

In Figure 4, (page 54) one can see that a majority of Virginia's community homes are funded through the local community mental health-mental retardation program. Seventy-five percent of these monies come from the state and 25 percent from local matching funds. Facility start-up funds are primarily community monies, although some Developmental Disabilities dollars are also used. Planning is underway to use Title XX to help support community homes. Title XX is now used for children's foster care and will be used to help maintain the new HUD Section 8 housing which is under development. The new HUD Section 8 project, developed by the state housing authority, depends heavily on local MH-MR boards to initiate the project. Housing control is local in Virginia, and Title XX funds are not fully used.

Virginia

Figure 5 (page 55) shows that Nebraska has developed a complete continuum of residential environments with the use of major funding methods. However, delivery of the full continuum of service opportunities is not consistent statewide.

Nebraska

PENNSYLVANIA COMMUNITY RESIDENTIAL FUNDING		
TYPE OF RESIDENCE	TYPE OF SERVICE	FUNDING SERVICES
Own Home	Public School Co. Office MH/MR	Training Social Work Service
Foster Home	Child Development Training - Home	Public School Co. MH/MR (Title XX) SSI - DI
Community Living: Special	Specialized Treatment	SSI - DI Co. MH/MR (Title XX) Private
Group Homes	Long-Term	Private Start-Up $ SSI - DI Co. MH/MR (Title XX)
Apartment 3 Types	Supervised Semi-Supervised Independent	Client Income SSI - DI Co. MH/MR (Title XX)
ICF - Skilled Nursing	ICF/MR Skilled	Private Start-Up $ Title XIX

Figure #2

PENNSYLVANIA COMMUNITY

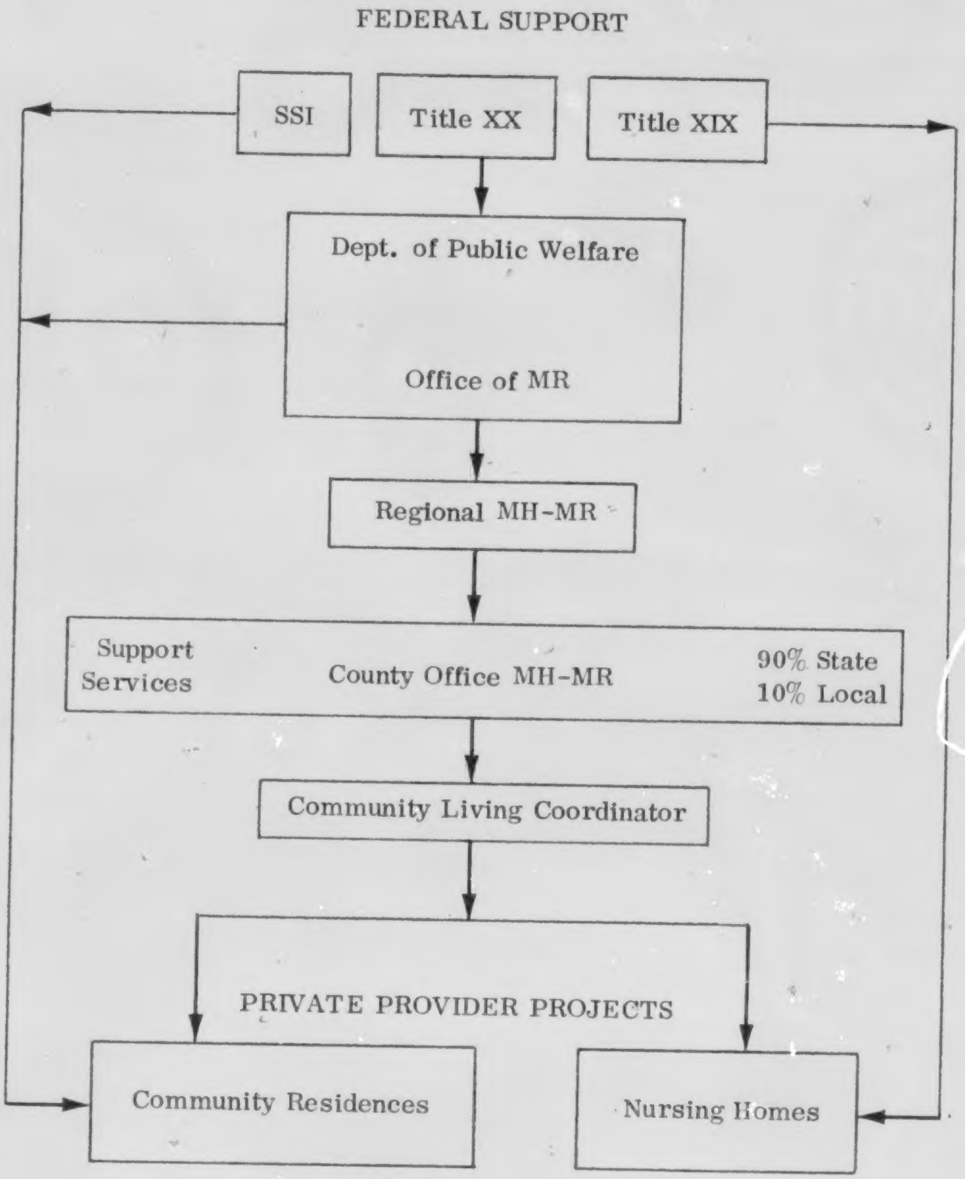

FEDERAL SUPPORT
SSI
Title XX
Title XIX
Dept. of Public Welfare
Office of MR
Regional MH-MR
Support Services
County Office MH-MR
90% State
10% Local
Community Living Coordinator
PRIVATE PROVIDER PROJECTS
Community Residences
Nursing Homes

Figure #3

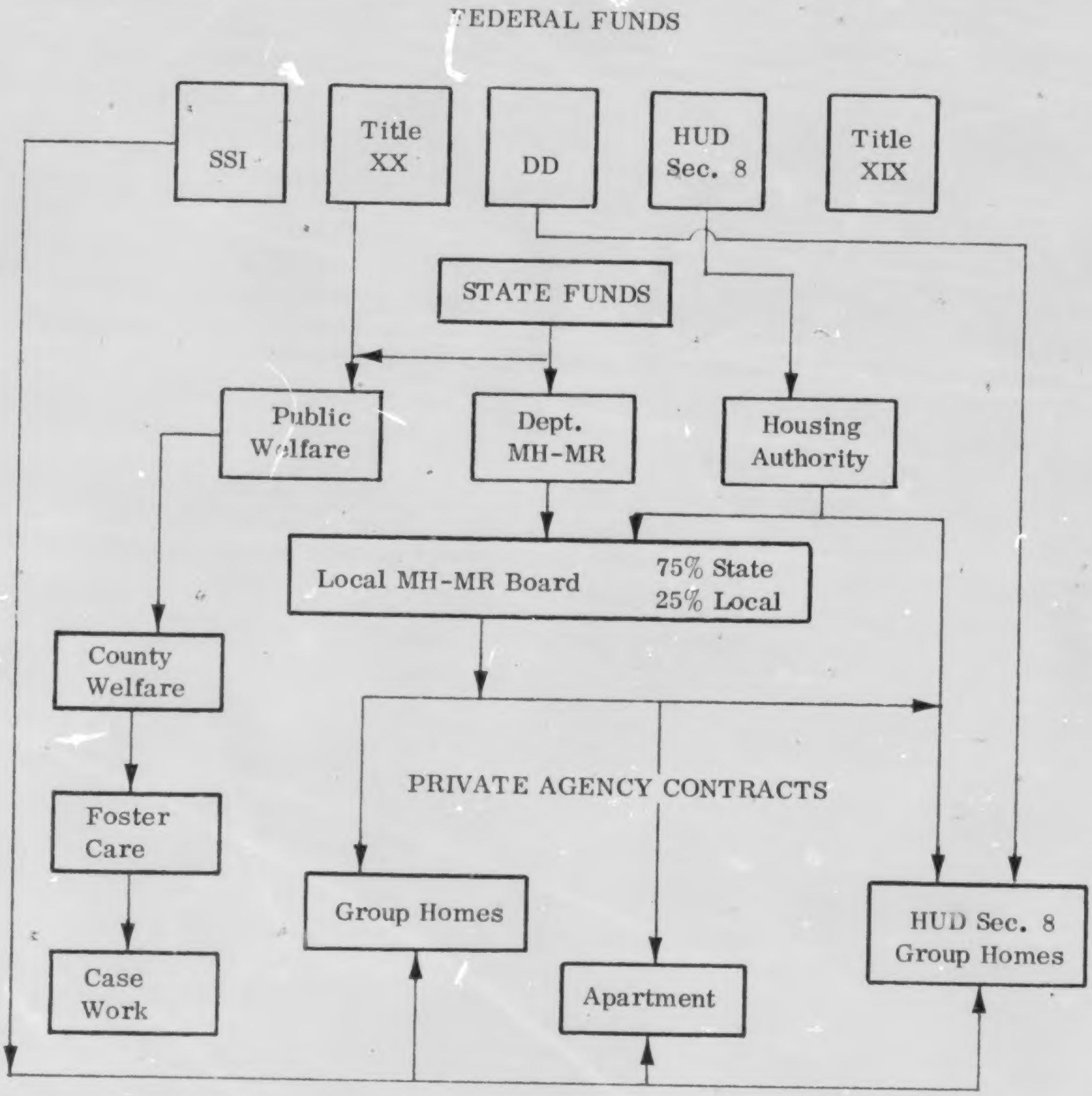

FEDERAL FUNDS
SSI
Title XX
DD
HUD Sec. 8
Title XIX
STATE FUNDS
Public Welfare
Dept. MH-MR
Housing Authority
Local MH-MR Board
75% State
25% Local
County Welfare
Foster Care
Case Work
PRIVATE AGENCY CONTRACTS
Group Homes
Apartment
HUD Sec. 8 Group Homes

Figure #4

NEBRASKA COMMUNITY RESIDENTIAL FUNDING		
TYPE OF RESIDENCE	TYPE OF SERVICE	FUNDING SERVICE
Own Home	Home Training Family Support	MR Regional Office DPI & Title XX Public School
Foster Care	Staff Service Training Maintenance	MR Regional Office SSI Public School
Group Home	Maintenance Staff-Programs Special Need	Client Income-SSI-DI MR Regional Office Co. Direct Supplement
Apartment (Supervised) (Semi-supervised) (Independent)	Maintenance Client Service	Client Income-SSI-DI MR Regional Office
ICF/MR	Maintenance Client Service	Title XIX Dept. of Institutions-Private
Skilled Nursing Home	Maintenance Client Service	Title XIX Dept. of Institutions-Private

Figure #5

Nebraska operates with regional control. Figure 6 shows the structure whereby regional mental retardation offices are supported with county dollars allocated on the basis of population. This is a form of millage used to match state and federal funds. Administrative accountability is quite neatly established in Nebraska.

title XX

People eligible for Title XX are programmed with these funds, while others are funded through the State Department of Institutions. State and local governments make up the 25 percent match to capture Title XX funds. All Title XX funds are used, and they provide considerable funding to the developmentally disabled population. The institutions in Nebraska are not plugged into the regional community system, although they are in the planning stages to do this. The institution uses nursing homes for placement, but these nursing homes are not coordinated with the regional system.

Michigan

Michigan has developed a continuum of residential environments, as seen in Figure 7 (page 57). Michigan uses all of the available funding streams discussed earlier. The State of Michigan has no defined organizational system for providing services, and accountability is difficult. The use of HUD funds in Michigan is more extensive than in other states. Title XX funds are used to supplement some community residential services. All Title XX funds are used by the state.

The state match of Supplemental Security Income (SSI) is sufficient to make the SSI payment a dependable support mechanism for maintenance of community homes. There is now a serious effort to use Title XIX to support community homes in Michigan. Institutions are also using ICF programs in a new well-financed state effort.

In Michigan community-based residential services may be operated by the state institution, the community mental health and mental retardation board, private non-profit systems and county departments of social services.

Time does not allow for an indepth review, but as we look at these states, we see that a large number of people are receiving SSI. The federal base for SSI is $167.00. In many states this base is subsidized. An SSI subsidy is arranged by the state legislature. Remember that before SSI states usually paid 25% of the cost of maintenance for eligible persons. When SSI came into being, some states opted out of any monetary contribution toward the maintenance of handicapped people. If we start with SSI or Disability Insurance as the base for the support of disabled individuals living in the community we have a fairly dependable start of support. The problems of earned income, poor understanding of mental retardation as a disability or the inability of public agencies to manage

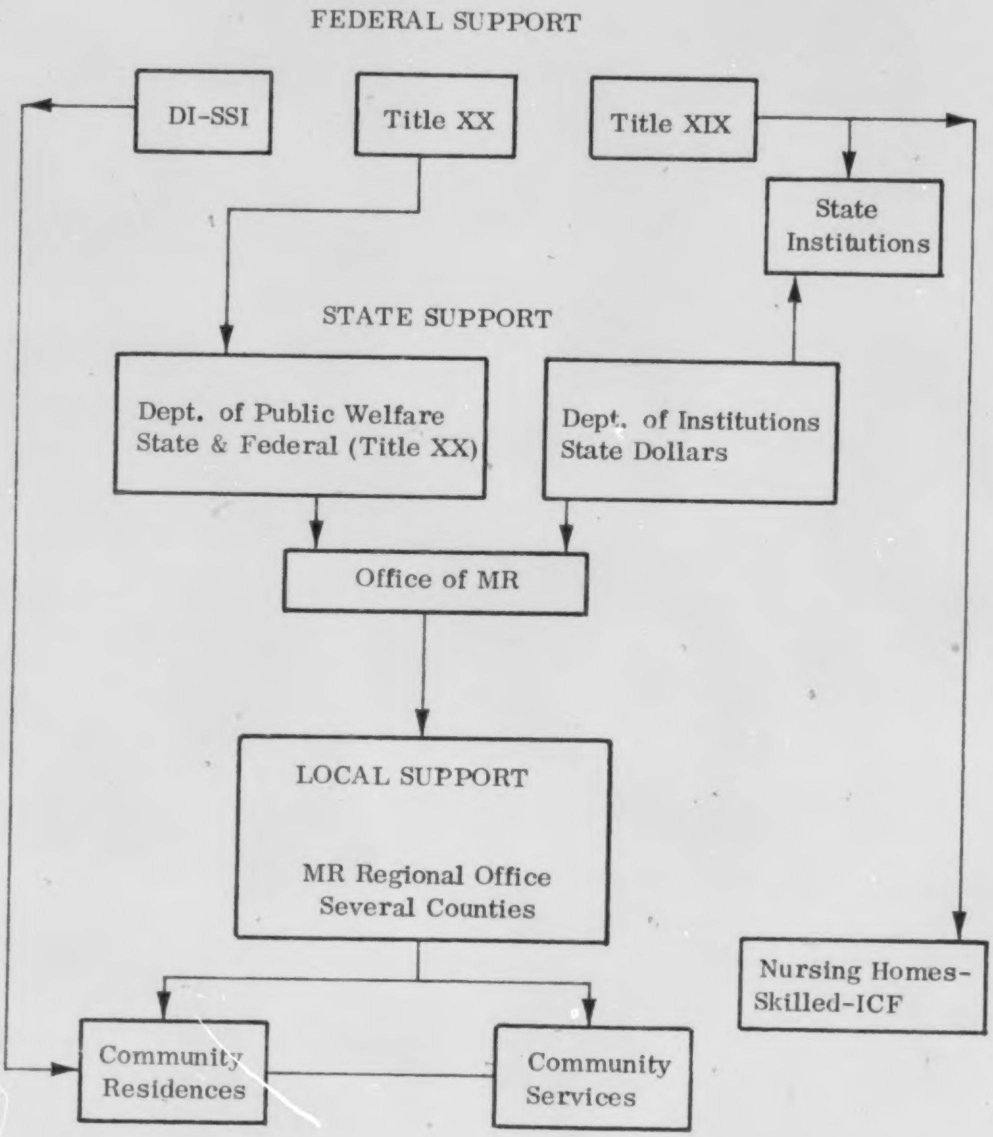

FEDERAL SUPPORT
DI-SSI
Title XX
Title XIX
State Institutions
STATE SUPPORT
Dept. of Public Welfare State & Federal (Title XX)
Dept. of Institutions State Dollars
Office of MR
LOCAL SUPPORT
MR Regional Office Several Counties
Nursing Homes-Skilled-ICF
Community Residences
Community Services

Figure #6

MICHIGAN COMMUNITY HOUSING

TYPE OF RESIDENCE	FUNDING SERVICE
Home Service	SSI-Federal & State Match State-Social Services Federal Title XX & State Match
Foster Home	SSI - Federal & State Match County MH
Group Home	SSI - Federal & State Match Social Services - Follow-up Title XX Community MH State + Local Funds Title XX (90-10%)
Special Group Homes MSHDA	SSI - Federal & State Match HUD - Sec. 8 - Sub. + Start-Up $ Social Services - Title XX - Private Agency
Contract Home	State Department MH Title XX County MH - Service
Sheltered Apartment	SSI - Federal & State Match County MH Local State
Skilled Nursing Home	Title XIX State Dept. MH - Special Service
ICF/MR	Title XIX

Figure #7

facilities for SSI clients are all solvable problems. Many have been eliminated by recent legislative action, thanks to the support of the NARC Governmental Affairs Committee.

- **Using the SSI funding base we can build a residential support system.**

  1. The state MR system adds program dollars to pay for staff and services.

  SSI

  2. It is now possible to subsidize resident maintenance cost without it being classified as unearned income.
  3. There is potential for Title XX funds to be used to support and maintain community residences.
  4. The mentally retarded individual is able to receive HUD Section 8 rent subsidies. This then adds to the support of the home and encourages a better quality home and the subsidy substantially reduces the amount of rent paid directly by the client.
  5. There are methods for using HUD funds to initiate new homes and renovate existing homes. There is also potential here for start-up funds and guaranteed loans.
     a. These can be arranged through the assurance that can be offered to an owner or builder when HUD Section 8 funds are available.
     b. Also, the use of HUD Section 202 offers project dollars to private agencies to build with and then pay off with rent subsidies (difficult to get).
  6. Some states have used federal Developmental Disabilities funds for start-up costs of community homes. In that the Office of Developmental Disabilities considers deinstitutionalization as a priority responsibility, there should be support for alternative residential programs. This resource has been used too little.
  7. Many states have had state funds provided to build community facilities. In addition, county and city governments have authorized funds to support housing for handicapped persons. These investments can receive HUD Section 8 dollars and the clients may also be eligible SSI recipients.
  8. Some states have been successful in using HUD Community Development dollars to renovate existing housing, to remove architectural barriers and to build community centers. These

have aided in making the community a better place for the retarded person to live.

Intermediate Care Facilities for the Mentally Retarded (ICF/MRs)

ICF/MR

The use of Title XIX funds has been a very attractive resource to many states. The many delays in preparing final regulations have opened doors to indiscriminate use of the Medicaid funds. As regulations are developed and client eligibility for this service is firmed up, we may find that only a small percentage of our mentally retarded population fits into the intermediate care facilities system. It is a resource and must be looked upon as a useful tool. We must consider the many levels of need for the individual with retardation and develop housing suitable to meet those needs.

state formula

The state's formula for financing ICFs gives considerable federal dollars to persons living in the ICF facility; 50 percent or more is possible. Potential ICF rates are considerably more than most other funding sources. If the rules are respected only those persons with medically related needs can use this type of facility.

Medical aspects of the certification and monitoring of Medicaid programs cause us to fear a return to the medical model. We must define the population that is suited for these facilities and not try to fit all clients into a convenient "box" because of a funding stream.

Of course, this program is popular to the private for-profit investor. It is easier to get these facilities going because of potential profits when a community identifies a need and advertises for a facility. Of course, the ICF regulations require our attention. The cost may become too high to fit into your current state allowance. If you must use ICF Medicaid funds you will be going to your state Medicaid agency to petition for an increased per diem rate to pay for the cost of an expensive system.

Planning

strategies

Are you asking yourself how all the resources used by these sample states have become available? States have worked through several planning systems to accomplish their effectiveness. Some of these strategies are listed:

1. Organization of ongoing advocacy activities;
2. Participation in state planning is a necessity. Existing mechanisms which have been used are:

   b. Medicaid ICF (Title XIX);
   c. Developmental Disabilities state plan;
   d. State housing agency;
   e. Department of MH & MR state planning.

3. Local planning that can be worked with to accomplish community support:
   a. Community Development Housing Assistance Plan (HAP)
   b. Community MH-MR boards;
   c. Comprehensive health planning system.
4. Interagency action on an ongoing basis is necessary.
5. Assess needs and develop means of presenting these needs to government agencies and the public through working with local and state planning systems.
6. Develop advocacy approaches to present client needs and to support a continuum of programming.

Efforts will continue by the NARC's Governmental Affairs Committee and the Residential Services Committee to provide technical assistance and further information on successful state systems to help you develop a system of support for a continuum of residential services in your community. "Let's get the job done" must become our motto. It takes common sense and a belief that mentally retarded people have the same needs and rights as others.

Administrative Issues

DENNIS POPP

From a management perspective I would like to begin by reviewing the principles that relate to the conceptualization, planning and implementation of residential services and necessary support services to ensure that the mentally retarded/developmentally disabled person can remain in the community. The principle of normalization, together with the developmental model of service delivery, must become the cornerstone of all agencies. Not only must services be comprehensive and thereby allow for increasing individual autonomy for the mentally retarded individual, but management must ensure that any model of a service delivery system must be based on the premise that: (a) human beings develop in a sequential and predictable fashion throughout their lives; (b) the rate and direction of development can be influenced by systematic training; and (c) certain conditions must be met environmentally and professionally if the training is to be maximally effective.

basic premise

Since the needs of every human being differ greatly, management must continue to plan for the design of an array of services that will meet each and every need of the individual at his own level and rate of development. In addition to the above principles directing management, there are laws such as the Vocational Rehabilitation Act, the Developmental Disabilities Act and the Education for All Handicapped Children Act. There are also ICF/MR regulations and the JCAH Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons standards that require management to provide individualized services. These laws, regulations and standards confront management with the responsibility for documenting that there are programmatic goals, that staff will meet the various needs expressed in the assessment findings and that there

regulations

are measurable objectives along with methodology and data reflecting how training or treatment is occurring.

Individual records are management's tools to chart the activities and interventions occurring with the individual. They also become a tool which lends itself to data collection for community-wide planning of services, coordination of such planning and development of additional services. These records also lend themselves to monitoring the quality of services delivered as well as providing funding accountability. Title XIX, ICF/MR funding, Title XX funding and Vocational Rehabilitation funding are all programs for the individualized purchase of services.

Figure #1 depicts the process management goes through in providing a functional individual program. The client, his family, various agency staff and other community agencies must all be included.

individual
program
plans

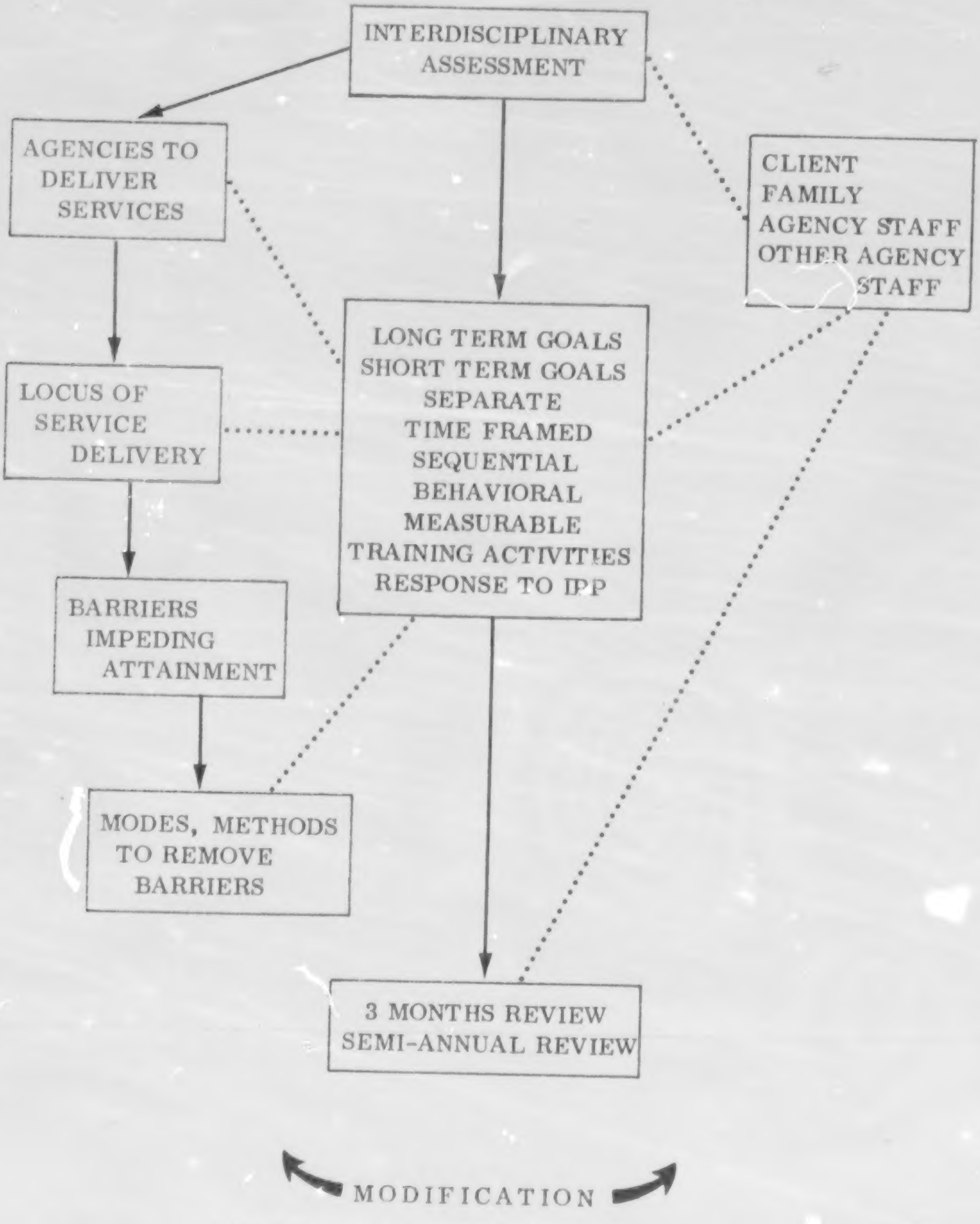
Beginning with assessment, management must determine the social and cultural values of the individual and his respective needs. In all phases of the Individualized Program Plan implementation, [illegible]eral questions remain: How is management to be legally and professionally capable of actually meeting the multiple needs of the developmentally disabled population with the most cost-effective, efficient and economical approach to delivering a multiple array of necessary services? What kinds of state and community support are needed? What additional laws are needed? What fiscal resources are required? What kinds of facilities are necessary? How many staff and what type of training must they have? These questions must be answered before management can provide an array of services.

human and
legal rights

Management begins with legal and philosophical directives to meet basis human and legal rights. If it is a governmental agency it will look to such things as state laws which mandate community services. If the laws are not available then the agency must develop position papers and policy statements which reflect its mission in carrying forth individualized and comprehensive services. Management from the private, nonprofit or profit-making corporations generally develop a mission statement reflecting their principles on individualization as well as state them in their by-laws and governing policies.

If management has the laws, can it implement them? If we look historically, the answer is yes. In the early 1800's management was concerned with individual needs and provided individual services. However, as numbers needing the services increased, the available financial resources decreased, and as professional knowledge of new training and treatment procedures grew too slowly, individual services declined. The services

FUNCTIONAL INDIVIDUAL PROGRAM PLANNING
CLIENT PROGRAM COORDINATION


INTERDISCIPLINARY ASSESSMENT
AGENCIES TO DELIVER SERVICES
CLIENT
FAMILY
AGENCY STAFF
OTHER AGENCY STAFF
LOCUS OF SERVICE DELIVERY
LONG TERM GOALS
SHORT TERM GOALS
SEPARATE
TIME FRAMED
SEQUENTIAL
BEHAVIORAL
MEASURABLE
TRAINING ACTIVITIES
RESPONSE TO IPP
BARRIERS IMPEDING ATTAINMENT
MODES, METHODS TO REMOVE BARRIERS
3 MONTHS REVIEW
SEMI-ANNUAL REVIEW
MODIFICATION

FUNCTIONAL RECORD KEEPING

Figure #1

became limited by the environment or the buildings previously designed for fewer residents. Management began to fit individual people and their respective individual needs into mixed groups. They went from single bedrooms into wards, classrooms into day rooms, etc.

programs

In the 1940's and 50's management again attempted to develop "programs" that would meet many needs of a group of individuals. Such things as vocational rehabilitation "programs," sheltered workshop "programs" and residential "programs" were conjectured. National accrediting standards were developed for these "programs" so that administrators could justify to citizens in the community that what they were doing was for the benefit of the individual as well as society. They measured programs by how many square feet should be minimal for clients and staff, what type and what number of professionals were required, what was the staff to client ratio, etc. They measured the structure of their programs rather than actual client development and proclaimed that since the program had such "high standards" and professionalism that the clients must be getting better. Examples of these types of program standards are found in the CARF accreditation standards. For example, we had a CARF review in Kansas last week of an adult training facility. The surveyors looked at program descriptions and safety factors such as "how high was the fire extinguisher." I think they read only two clients' records, did not speak to any clients and did not speak to any staff involved in training clients. In essence, they looked at what was written about the program - not what the program was doing to the client. This type of review does not measure what consumer groups have demanded that management deliver.

standards

One hundred and sixty years later management has come full circle and is again looking at the developmentally disabled as individuals requiring numerous services which are part of a variety of programs which are operated by a variety of agencies and located within numerous types of settings. There are also new accreditation standards which now are based on services provided to individuals. These were adopted in 1973 by the Accreditation Council for Services for the Mentally Retarded and Other Developmentally Disabled Persons of the Joint Commission on Accreditation of Hospitals.

assessment

As management attempts to meet the individual's needs and not the facility's or professional staff's needs, changes can be seen, beginning with the types of assessments that are being administered. Diagnosis now begins with a general development assessment of the total person's needs and abilities. We then add to it psychology, speech and hearing, occupational therapy, social work, medicine, etc., for additional diagnosis, all looking at the total person. In the recent past it was very difficult to determine what to do with a mentally retarded or developmentally disabled individual who had only a medical or psychological assessment. Now, to find physicians who will made a diagnosis of mental retardation without the backup of assessment instruments from other disciplines is becoming more rare.

barriers

Mr. Jerry Walsh, in his paper on The Implementation of Community and Home Re-entry, points out some of the barriers which affect the development, integration and utilization of community residential facilities. He points out that there are negative attitudes in neighborhoods. Neighbors: (a) desire to put the mentally retarded on a farm where they "won't get hurt," or (b) fear potential effect on "their property value."

There are also the barriers erected by parents who: (a) fear their child will fail with less restrictions; (b) are concerned that they have failed as parents; and (c) continue to have feelings which they need to protect. The third barrier for these community services is public administrators who: (a) issue rigid regulations; (b) keep threatening the loss of funds: (c) insist upon multiple agency inspections: and (d) do not plan for coordinated outcomes. Probably the most threatening barrier to management providing community services is the multiple regulations impacting upon the delivery and funding of these service.

patterns of service

Management is constantly faced with decisions. If it is a state management system, managers must make such simple decisions as: Will all the needed services be state operated? Will some of the services be state operated and some of the services regionally operated? Will most of the services be privately operated with the state purchasing services for the client? My contacts reveal that a combination of public and private agencies operating a variety of services has been the primary pattern of service development.

Generally, state agencies maintain ownership and operational responsibilities for public residential facilities along with some regional coordinating responsibilities.

funding

After management decides which service or services they wish to provide, they must carefully review the way in which federal laws are written, the regulations interpreted and the funding patterns developed. For example, if the state agency decided to utilize Title XIX funds within the operation of state facilities, the agency must review which buildings and programs would now meet ICF/MR regulations. In the past we had to carefully determine which services were "medical services" in order to qualify for limited Title XIX reimbursement. We are still not certain about limits of the "medical service" definition since practically all of our services are now eligible for funding. Most of our state institutions offer these medical and rehabilitation services because we can receive nursing homes

50 to 90 percent of their cost from the Federal Government. However, when the same rules and regulations are applied to community nursing facilities (which are usually 50 beds or more) the private owners must assess the economics of whether or not they wish to serve the mentally retarded. Hundreds of these nursing facilities cannot meet the ICF/MR standards and will require a number of expensive architectural and staffing changes.

eligibility

If the mentally retarded person is moved from a public Title XIX supported facility into a small community-based residential facility, he is no longer a medical recipient or patient; he is now thought of as a community citizen and/or client who is living in a smaller group facility. As his residential status changes (not necessarily his service needs) he also changes his eligibility for financial support. He is no longer primarily supported with Title XIX funds (except in Minnesota). He now must go through eligibility for Supplemental Security Income, Title XIX for general medical services in the community and social service funds if that particular state has not reached its Title XX lid for social services. Management must determine if this individual is capable of living on $167 per month SSI income, plus medical. That conclusion is not difficult to reach, but it is difficult to find more funds for living expenses.

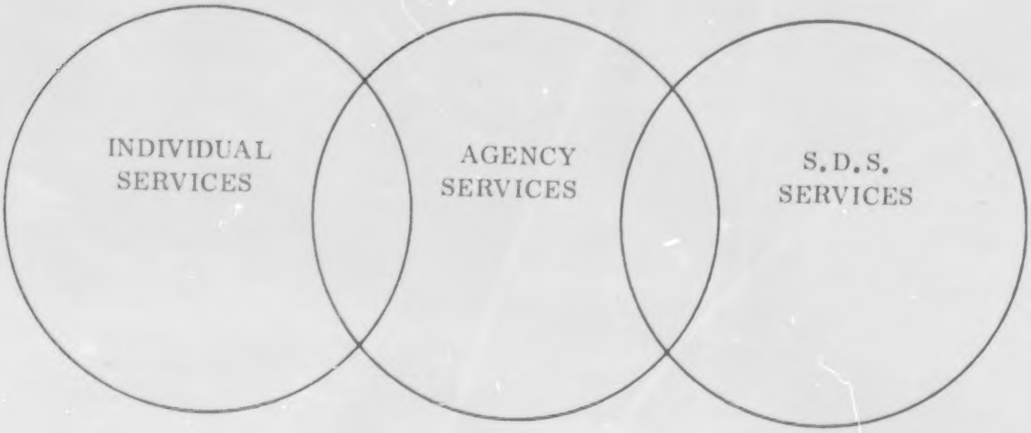
coordination of funding

Let's throw in some other interpretations that keep management confused in its decision making process. If a mentally retarded individual happens to be of school age and lives in a Title XIX public facility, he may or may not be receiving tax dollars designed for free public school education. There is still a great deal of concern and question as to who is responsible for his education. Are the medical services delivered in such a way as to be seen as educational services? Does the local public school district have responsibility for the payment of his educational services if he lives in a public Title XIX facility? Now, if that same individual of school age were living in a community residential facility which does not receive Title XIX support, he could attend a free public school program. So, as you can see, funding patterns and the provision of residential services are not solely determined on the needs of the individual, although this is the basis for most laws.

programs

The laws have been interpreted through regulation and practice to meet the financial needs of management who operate "programs" or "facilities" and not individual services. Programs, as all of you can well attest to, can be defined in as many different ways as we may wish to define them. We have today innumerable definitions of an educational program, of a residential program, of a medical program, of a rehabilitation program, etc. When the philosophical base and the implementation of laws conflict with the intent of the legislation or what the consumers desired, then

Multiple Relationship Evaluation Standards for Community Agencies



Case Finding
Entry
Follow Along
Individual Program Plan
Client Prog. Coord.
Protective Services
Personal Advocacy
Guardianship
Health Needs
Mobility Needs

Case Finding
Entry
Assessment
Developmental Needs
Employment & Work
Religious Nurture
Recreation & Leisure
Family Related Services
Volunteer Services
Research
Records
Administration

Case Finding
Entry into the SDS
Coordination
Resource Information
Agency Advocacy
Community Education
Prevention
Manpower Development

PROGRAM EVALUATION

Evaluation Requires:

1) An assessment of an individual's developmental growth
2) An assessment of agency developmental growth
3) An assessment of community developmental growth as reflected by relationships between agencies and the community at large

Figure #2

management will not be able to consistently administer the services provided. Management is continually confused about whether their interpretation of the laws and regulations are correct and, if not, will they receive a financial audit exception.

community agencies

I would like to present my next few remarks from the perspective of meeting individual needs in concert with a variety of community agencies. As specialized developmental disabilities agencies work together to develop comprehensive services in a community or region they do so based on principles generally found in the standards of the Joint Commission's Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons. There are three primary principles guiding their efforts.

responsiveness

The first principle of "responsiveness" requires that both the needs of the individual and the unique community be responded to.

availability

The second principle is that of "availability" and ensures that the services will be available to those who need them.

accessibility

The third principle is that of "accessibility" which means that the community's discrimination practices are modified, the buildings are accessible, that there is an active community informational program and that there is a fixed point of information along with numerous referral services.

single service agencies

In July of 1974, an Advisory Committee on the Accreditation Process for a Service Delivery System was formed, with Mr. T.K. Taylor as its staff coordinator. Its charge was to determine if a service delivery system could receive accreditation. The committee realized that a single agency could not provide the complete array of services required by developmentally disabled persons. Some agencies could only provide a single service such as information and referral. Some may provide information, referral, diagnosis and evaluation. Some provide three, four, five or six services. The total service delivery system, therefore, becomes concerned with how to most effectively and efficiently coordinate and deliver such services. Figure #2 lists services that national accreditation staff may review when they conduct surveys of an agency or service delivery system.

When viewing the variety of community service delivery patterns we see some agencies being brokerage firms which sit back and buy each and every service needed. This is occurring in vocational rehabilitation and Title XIX programs. Some states, such as California, are also setting up regional brokerage agencies. We see some specialized agencies performing assessment functions by providing diagnosis and evaluation, and then referring to the appropriate agencies which have one or more of the needed educational, training or treatment services required. Since none of these individual agencies can be all things to all the developmentally disabled within the community, together they form a nucleus for the development of a comprehensive community services delivery system. Figure #3 portrays the program and service arrangements necessary for the development of a service delivery system.

comprehensive system

This community consortium of agencies must continually plan together if a comprehensive service delivery system is to exist. Such planning, when coordinated by one agency or group, reduces fragmentation, isolation and duplication of services. It enhances the sharing of professional resources and expertise. Planning and coordination also stimulate cost effectiveness through the utilization of all community resources rather than the duplication of these resources.

change agents

When these agencies act in unison they are seen as change agents because they are continuously reviewing themselves and the needs of the population group which they set out to serve. These are usually agencies which are working together but have different functions, responsibilities, resources, skills, etc. When these agencies come together as a consortium they demonstrate a wider range of functions and services in terms of numbers of individuals they can serve and the age range of their clientele. In addition, the severity of the handicapping conditions they serve is generally broadened.

evaluative instruments

The facilities in which these services are provided are always a major concern to the community, to the developmentally disabled individual himself and to the funding agencies. Therefore, several evaluative instruments have been designed which attempt to ensure that the services are provided in a suitable physical structure. These evaluation criteria can be found in such instruments as PASS,[1] AC/MR-DD[2] accreditation standards, ICF/MR[3] regulations, Architectural Barriers Act, OSHA[4] Standards, State Licensing Standards, fire and safety codes of

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[1] Program Analysis of Service Systems

[2] Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons

[3] Intermediate Care Facilities for the Mentally Retarded

[4] Occupational Safety and Health Administration of the Department of Labor

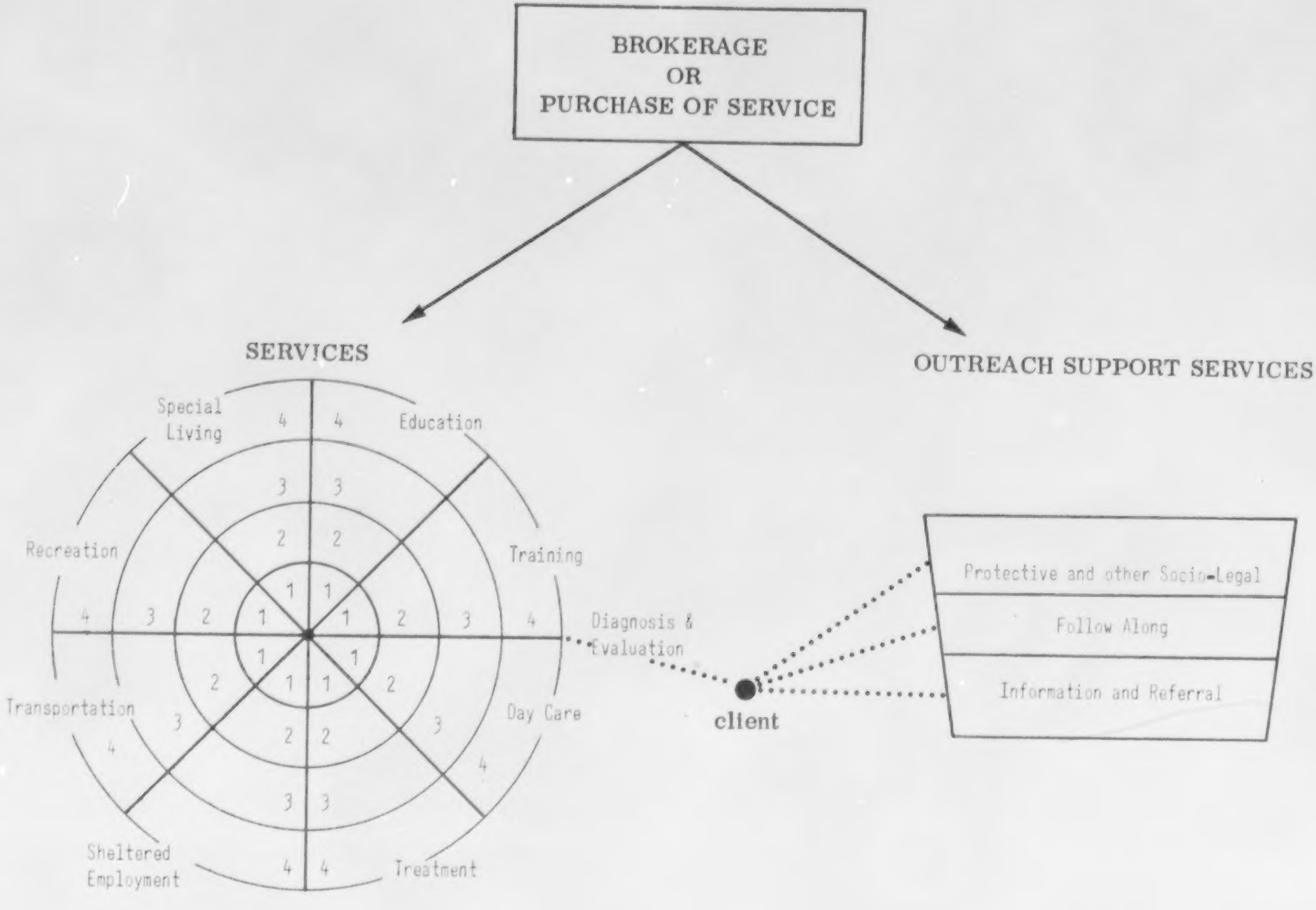
BROKERAGE
OR
PURCHASE OF SERVICE
SERVICES
OUTREACH SUPPORT SERVICES
Special Living
Education
Training
Diagnosis & Evaluation
Day Care
Treatment
Sheltered Employment
Transportation
Recreation
1
2
3
4
client
Protective and other Socio-Legal
Follow Along
Information and Referral

Figure #3

federal, state and local governmental units, and I am sure I've left out several others. These types of external standards have a major impact upon management and its planning to obtain buildings that can meet a variety of service needs.

environments

Management has to decide the size of the buildings and whether they should be constructed, purchased or rented. Where should they be located? For whom should they be designed? What type of physical, mental and social needs should the buildings be able to accommodate? Who is responsible for the maintenance and upkeep? What kinds of insurance are necessary? Are there zoning restrictions? To what extent should the values of observation, protection and structural security govern the handling of individuals? What are the therapeutic effects of color? What are appropriate noise levels? How pleasant should the environment be, either for sleeping or day programming? What is the ideal balance between openness and architectural stasis? How is the structure identified within the community? How does the community relate socially to the structure and its programs? What are the limiting factors for climate, lighting, air conditioning, hearing and environmental pollution? What is the physical ability to control disease, accidents and other such dangers?

services

When residential services are finally provided, management must decide such things as how is food purchased? Who prepares the food? What types of staff, if any, are necessary for food preparation? What are the laundry potentials? What are the transportation options available? Where can the resident find recreation or leisure time activities? Who provides the employment, work training and educational opportunities? Where are necessary medical services offered? Is there an opportunity for privacy?

staff

Management has to go the next step by hiring staff qualified to provide residential services. If it includes health related service, then registered nurses, licensed practical nurses, physicians, occupational therapists, physical therapists, etc., must be available. If it includes an educational service, there must be educators, trainers and counselors. If it includes recreation/leisure-time service then there must be recreational therapists, adjunctive therapists and aides. If it includes personal and social adjustment services, then there must be psychologists, psychiatrists and social workers. Then management determines: What staff ratio is necessary? What salaries are competitive? Are there unions? How will management supervise and monitor? Figure #4 recapitulates some of the issues that must be resolved and coordinated if some minimal services are to be provided.

STRUCTURAL ISSUES

1. Build or Purchase
2. Rent or Lease
3. Location in Community
4. Accessibility
    - A. Exterior
    - B. Interior
5. Aesthetics
    - A. Color
    - B. Noise Levels
    - C. Temperature Control
6. Openness or Structure
    - A. Privacy for Client and Staff
    - B. Openness for Interaction and Service Delivery Feasibility
    - C. Security
7. Design to Accommodate
    - A. Children
    - B. Adults
    - C. Nonambulatory
    - D. Families
    - E. Number to be Served
8. Temporary or Permanent Usage

STAFFING ISSUES

1. Professionals
    - A. Which Disciplines
    - B. What Level of Training and Experience
    - C. How Many of Each
2. Paraprofessionals
    - A. What Level of Training and Experience
3. Recruitment
4. Salary
5. Unions/Civil Service
6. Continuing Education Opportunities
7. Supervision
8. Monitoring

FUNDING ISSUES

1. Title XIX
2. Title XX
3. SSI
4. Insurance
5. Community Development Funds
    - A. State
    - B. Local
6. Private
7. Dept. of Trans.
8. Revenue Sharing
9. HUD
10. Education

MANAGEMENT ISSUES

1. Regulations and Standards
2. ICF/MR Regulations
3. Architectural Barriers Act
4. Zoning
5. State Licensing
6. State and Local Fire/Safety Regulations
7. OSHA
8. Fiscal Accountability
9. Federal Day Care Standards
10. Wage and Hour Regulations
11. Accreditation by Joint Commission
12. PASS
13. IPP Records
14. Advocates

Figure #4

staff development

A frustrating and ongoing problem faced by management is related to the area of personnel. Management must determine: Who do they recruit? What is the availability of substitutes, especially for residential services? What are the most functional job descriptions? How do you evaluate personnel so that you do not offend unions or civil service regulations? What salary do you pay and what fringe benefits do you offer? What numbers and types of professionals should be hired? What should be the entrance competency level or basic knowledge level of staff? How do you upgrade skills of staff?

interdisciplinary process

The roles and functions of professional staff, particularly within residential programs, vary considerably from agency to agency. A psychologist in one facility may be an administrator, where in another he is primarily involved in assessment and in another he is involved in personal and social adjustment training. As we identify the professionals and staff necessary to conduct the services, we must also develop the methods by which they communicate with one another, work with one another, plan with one another. The interdisciplinary process not only must exist, but a transdisciplinary process must be developed. Management has had to face many of these issues without a great deal of help from universities or other traditional labor markets. They have had to develop training programs to ensure competence of staff working with the mentally retarded individual. An ongoing question for management is, do the staff have the knowledge to perform, or does the system which management has developed allow for the knowledge to be utilized? In other words, if something is not being done that should be done, do the staff need training or do we need to determine how to use the knowledge we already have (which may be accomplished by various management techniques)?

inservice training

In trying to assist community agencies with this problem, Mr. Dave Svoboda, Coordinator of Inservice Training on our staff, has collected various training packages that public and private agencies are utilizing for assessment of staff and for inservice training purposes. There are general informational packages being developed such as one recently designed in Kansas entitled, Basic Training Manual for Service Providers. This training manual has the following training programs:

1. Overview - Etiologies of Developmental Disabilities and the Current Federal and State (Kansas) Administration of the Developmental Disabilities Program;
2. Human and Legal Rights;
3. Philosophies of Service Delivery;
4. Diagnosis and Evaluation (Assessment);

5. Individualized Program Planning;
6. Systematic Learning (Behavior Management);
7. Community Relations.

In addition, the last three chapters deal with providing services in:

8. Residential Facilities;
9. Adult Day Training Facilities;
10. Child Day Training Facilities.

Where this manual has attempted to provide some general basic information in many areas, other packages have gone more deeply into specific areas.

The Florida Department of Health and Rehabilitative Services has provided an excellent guide to materials for the severely handicapped. This guide provides a bibliography and listing of resources for staff to utilize as needed. This type of guide requires staff to have some initial basic knowledge and skill. It does, however, provide a great deal of information that staff can use at various levels of their growth and development in such areas as assessment, intervention, outreach and model projects.

The Michigan Department of Mental Health and Social Services has developed a 456-page document entitled, Adult Foster Care Provider Training Manual, which has five chapters:

1. Adult Foster Care;
2. Behavior Management;
3. Programs, Activities and Services;
4. Health Care; and
5. Home Management Administration.

The Pennsylvania Department of Education has developed a Training Model - Individual Assessment Guide. This is geared more toward children's assessment and takes the assessment information and breaks it into individual units.

There have also been several packages developed on the Individualized Program Plan. Kansas is in the process of conducting ten sessions on how to develop an IPP through "telenet" across the State of Kansas. There is also a manual by Houts and Scott entitled, Goal Planning with Developmentally Disabled Persons, that has with it an instructor's manual and supervisor's manual, along with a cassette tape. Texas Tech University has developed a two-hour video tape on how to develop an IPP. An excellent paperback is one entitled Preparing Instructional Objectives by Robert F. Mager. There are additional specific training packages such as the "Managing Behavior Series" by H & H Enterprises, Inc., Lawrence, Kansas. There are others which I'm sure I have left out of this list.

individual needs

With the complexity of problems and needs presented by the developmentally disabled population, agencies must develop a continuum of training for staff from the beginning preservice training activities of all staff to an ongoing inservice training program which will meet the various skill and knowledge areas that all staff require. Management is faced with the fact that staff develop at various individual rates as do their clients.

coordination

We must continually remember that the complexity of individual needs is further complicated by the complexity of an agency and its one or more services. This complexity expands when we view a community service delivery system. Many times this appears as mass confusion. Coordination of all of these entities into a non-duplicated efficient means of delivery has been and remains a tremendous challenge to all management. However, parents and advocates can help management establish the individualized services along with a wide range of services by remaining involved and knowledgeable.

I would like to close by sharing with you a report from the Morrison Associates, the Mental Health and Mental Retardation Report, November 17th issue. The General Accounting Office reports summarized herein begin to give me some hope, as a public administrator, that there may be some way to coordinate all of the federal rules, regulations and funding activities.

GAO report

The General Accounting Office (GAO), which is a branch of the Congress, has recently conducted a study on the "deinstitutionalization" effort. In essence, the report states that improvements are needed to help the mentally disabled return to and remain in the community. The GAO examined a variety of our management problems. Their report broadly defines deinstitutionalization as a process of preventing unnecessary admissions and retentions in institutions; finding and developing appropriate alternatives in the community for housing, treatment, training, education and rehabilitation of developmentally disabled persons who do not need to be in institutions; and improving the conditions, care and treatment of those who need institutional care. Some of the following programs were reviewed and their findings are summarized below:

1. As for the Title XIX (Medicaid) program, the GAO felt that this program was not completely favorable to our efforts. Large numbers

of developmentally disabled persons are transferred from facilities having specific standards for care and treatment and placed in skilled nursing homes and ICF facilities which generally do not have to comply with the standards. As I said earlier, there are several hundred nursing homes which are not going to meet ICF/MR regulations.

2. The cost of mental health and mental retardation care has been taken from mental health and retardation budgets and put in welfare budgets. The responsibility for funding has also shifted from state to federal budgets. The responsibility for the care of developmentally disabled persons is also shifting from the mental health and retardation specialized system to the welfare system. The GAO report pointed out that there is a need to prepare annual reports on the development and implementation of comprehensive services. Documentation is also needed of cases where persons were placed in an ICF because of the lack of community alternatives and the exploration of other alternatives. The preparation of release plans which include arrangements for appropriate services, protective service, supervision and follow-up are also required.

budget
changes

3. The GAO report recommends that the Department of Health, Education, and Welfare give states incentives to place developmentally disabled persons in the most appropriate setting, avoiding unnecessary placement in ICFs and skilled nursing homes. Similarly, HEW should ensure that mental hospitals and institutions for retarded individuals are included in the validation surveys and other reviews of state utilization control programs.

appropriate
placements

4. The report attributed many of the problems associated with deinstitutionalization to the lack of an effective management system that clearly defined objectives, roles, responsibilities, actions and evaluations to be carried out by the various agencies in the effective transfer of individuals from institutions to communities.

management
system

A systematic way to finance deinstitutionalization is needed which would assure that persons were placed in the least restrictive environment, most appropriate to their needs, with necessary services in the most cost-effective manner. Criteria standards are necessary for defining adequate or acceptable community placements in the least restrictive environment. The General Accounting Office indicates that Congress should designate a committee with responsibility to oversee all federal efforts toward deinstitutionalization.

5. The GAO also recommends to HEW: (a) that a clear and consistent federal role in the mental health and retardation area should be

determined and recommendations made to Congress for a long-term approach to alleviating the problem related to deinstitutionalization; (b) HEW should evaluate the need and desirability of providing other types of care outside of ICFs; (c) HEW should determine how best to ensure that state agencies administering HEW supported programs develop and implement effective case management systems for persons being released to ensure that the individual's needs are fully assessed, that arrangements are made for appropriate placement and needed services, that there is sufficient follow-up and that there is responsibility and accountability which is clearly defined.

social services

6. The report looks at social services and recommends that social service funds be utilized along with SSI to prevent admission to state institutions. They looked at vocational rehabilitation and found that vocational rehabilitation agencies had not been providing sufficient services to the more severely developmentally disabled. Some states had even adopted policies or definitions which had categorically excluded certain segments of the developmentally disabled populations without an evaluation of an individual's potential as required by law. The report also notes that vocational rehabilitation should look at the definition of severe disability and that it be clarified as to how it relates to the retarded. Consistent procedures and criteria should be used for classifying persons as retarded. Vocational rehabilitation must establish criteria and procedures to ensure that decisions to deny vocational services to the developmentally disabled on the basis of their inability to achieve a vocational goal be made only when a lack of vocational potential has been demonstrated beyond any reasonable doubt.

dispersed authority

7. The Office of Management and Budget has found 135 federal programs administered by 11 major departments and their agencies all of which potentially impact on the delivery of services to the developmentally disabled. This is almost impossible to coordinate at a state level.

8. They also reviewed the Department of Housing and Urban Development and recommended that HUD direct their area and regional office personnel to work more closely with federal, state and local mental retardation officials to ensure that housing provided to the developmentally disabled is appropriate.

9. They looked at Labor and asked: Are your Comprehensive Employment Training Act funds being used effectively? Are they being used for institutional or other residential programming?

If this report and its recommendations are implemented, I think we have a chance to develop, coordinate and deliver a comprehensive array of services which will meet the individual needs of the developmentally disabled population.

The following are examples of staff development materials which are referenced in the preceding speech.

MANAGING BEHAVIOR SERIES - (H & H Enterprises, Inc., P.O. Box 3342, Lawrence, Kansas 66044) - This series of eight paperbacks explains in detail the theories behind and techniques of behavior modification. Part 1 - The Measurement of Behavior; Part 2 - Basic Principles; Part 3 - Applications in School and Home; Part 4 - New Ways to Teach New Skills; Part 5 - A Teacher's Guide to Writing Instructional Objectives; Part 6 - Summaries of Selected Behavior Modification Studies; Part 7 - Teaching a Child to Imitate; Part 8 - Teaching Speech to a Nonverbal Child.

staff
development
materials

PREPARING INSTRUCTIONAL OBJECTIVES - By Robert F. Mager (Fearon Publishers) - This 136-page paperback is an excellent guide for learning how to write behavioral objectives. The book discusses the purposes of objectives, as well as their qualities and components. It contains several "feedback" exercises, so the reader knows whether or not (s)he is on the right track.

GUIDE TO MATERIALS FOR THE SEVERELY HANDICAPPED - Florida State Department of Health and Rehabilitative Services, 1311 Winewood Blvd., Tallahassee, Florida 32301. This guide comes in four parts - Assessment, Intervention, Outreach and Model Projects. The assessment part describes over 30 different assessment scales and checklists. There is a cross-reference index where each assessment is subdivided into skill categories with an indication of the number of items for each category represented in the instrument. The skill categories include social, cognitive, dressing, eating, toileting, working, gross motor, fine motor, language, numbers and reading.

The intervention part contains six sections. The first section is on individualized programming and discusses the elements of an IPP, including goals, task analysis, behavioral objectives, instructional strategies and evaluation. The second section is an annotated bibliography of 65 publications. The bibliography is divided into two sections containing books on behavior modification and instructional materials. The third section contains a list of 99 articles from various periodicals. The articles are divided into eight subject areas, including vocational, social, self-help, motor, language, cognitive, behavior modification and general topics. The fourth section lists a few of the many vendors of toys, equipment and adaptive devices. The fifth section is another annotated bibliography of 45 instructional programs. These programs contain materials which have been developed for nonhandicapped children (birth to six years) but are adaptable for use by the handicapped. The final section is a toy guide for children between one and five years of age. There are four guides broken down into one-to-two, two-to-three, three-to-four and four-to-five year increments. Each guide lists types of materials, the purpose of each type and some samples of what can be used.

The outreach part is divided into two sections, both of which suggest publications and materials for use with and by parents whose children are at home. The first section contains 35 entries which are annotated. The second section contains 58 entries (over 20 of which are instructional programs for skill development) which are not annotated here, but many of which are annotated in the Intervention part of the guide.

The fourth part of the guide is a booklet on Model Projects. This part differs from the other three in that it is not a bibliographic resource tool, but instead presents articles about five federally funded projects for services to the severely handicapped. These articles describe current efforts throughout the country in the development of new and effective materials. The four areas of curriculum development, public school models, rural education models and audio-visual materials are presented.

ADULT FOSTER CARE PROVIDER TRAINING MANUAL - Michigan Departments of Mental Health and Social Services. This 456-page document is a very good program for pre- and in-service training. It contains five chapters: 1) Adult Foster Care; 2) Behavior Management; 3) Programs, Activities and Services; 4) Health Care; and 5) Home Management Administration. The first chapter gives an overview of some of the complexities involved in providing care to adults. Chapter two is broken into eight parts and is a pretty thorough description of the principles, techniques and legal and ethical issues of behavior control. The third chapter is broken into three main areas: the state assessment plan, community-based programs and in-home programs. The third area of this chapter is further divided into basic self-care and basic living sections. Chapter four has seven sections dealing with medical records, nutrition, exercise, accident prevention, nursing procedures, diabetes and drugs. The last chapter is composed of six sections including budgeting, accounting, personnel policies, purchasing, client accounts and insurance. An index assists in quick reference for many topic areas.

PENNSYLVANIA TRAINING MODEL INDIVIDUAL ASSESSMENT GUIDE - Pennsylvania Department of Education. The Pennsylvania Training Model Educational Planning System is designed to assist teachers in the development of specific programs for the severely and profoundly mentally retarded and multi-handicapped from a broad assessment of the individual's total needs. There are four major steps in the model: First, an overview of the child's skill development is obtained from the Curriculum Assessment Guide; second, each of the major areas of interest are broken into smaller developmental units from the Competency Checklists; third, the smaller developmental units of interest are then further reduced into sequentially smaller steps through task analysis; and, fourth, an educational objective is written and a prescriptive teaching approach is employed to achieve this objective. Should the individual not progress at the rate desired, the system provides for a functional analysis of all the variables involved to provide the teacher with the needed information to modify the program.

GOAL PLANNING WITH DEVELOPMENTALLY DISABLED PERSONS - Peter S. Houts and Robert A. Scott. This is a five-session training program on the procedures involved in developing an individualized program plan. The handbook for learners is very well written and easy to understand. It offers very simple alternatives for record-keeping. The entire package can be ordered with an Associate Instructor's Manual and a Supervisor's Manual on evaluating plans. There is also a cassette tape which can be used to augment the instructor's efforts.

INDIVIDUAL PROGRAM PLANNING - Kansas State Division of Mental Health and Retardation. This is a training program which is designed to present the fundamental ideological precepts of the IPP and then discuss implementation and evaluation through a treatment team, including techniques and procedures. There is a package of color video tapes and a collection of written materials to augment the tapes. The individual modules of the program include: 1) an overview of individualized programming; 2) program coordination and family involvement; 3) team concepts and strategies; 4) clinical assessments; 5) behavioral assessments; 6) writing objectives; 7) data collection; 8) teaching strategies; and 9) review and revision of objectives and program placements. The program was designed to present information to reflect national accreditation standards (JCAH, CARF, etc.) and P. L. 94-103 (the Developmental Disabilities Act). These tapes are expected to be available for use in January 1977.

BASIC TRAINING MANUAL FOR SERVICE PROVIDERS - Kansas State Division of Mental Health and Retardation. This manual was designed to provide staff with some basic information on providing quality services. The manual does not provide indepth training in any area; rather, it provides an overall philosophical and procedural guide which should serve as a starting point for an agency's inservice program. The philosophies of normalization, the developmental model and individuation run throughout the ten chapters. The chapters contain information on: 1) etiologies of developmental disabilities and the current federal and state (Kansas) administration of the developmental disabilities program; 2) human and legal rights; 3) philosophies of service delivery; 4) diagnosis and evaluation (assessment); 5) individualized planning; 6) systematic learning (behavior management); and 7) community relations. In addition, the last three chapters deal with providing services in: 8) residential; 9) adult day training programs; and 10) child day training programs. Each chapter contains a list of suggested readings for further information on the content discussed in the chapter. This manual is expected to be made available by February 1, 1977.

THE IMPLEMENTATION OF COMMUNITY AND HOME RE-ENTRY - 4th International Congress of the International Association for the Scientific Study of Mental Deficiency, by G. F. Walsh. August 1976.

Laws and Regulations

PAUL FRIEDMAN

From a lawyer's point of view there wasn't an area called "mental health law" or "mental retardation law" before the 1970's. Judges and legal scholars paid minimal attention to how people got into and out of institutions, but virtually no thought went into what happened after the doors of the institution closed behind a person who had been committed, or admitted, or what services these people might be entitled to in the community. It would have been fair to say at the beginning of the seventies that mentally retarded persons, like other underrepresented and powerless minority groups in our society, had virtually no rights at all. A lot of institutions were so severely understaffed and underfinanced that people weren't even safe in life and limb. They weren't protected against harm, let alone given some kind of affirmative habilitation program. And in the community mentally retarded persons were denied a whole gamut of basic rights and privileges that other citizens in our society enjoy. There was a kind of blanket, stigmatizing presumption that mentally retarded persons were incompetent to vote, to drive, to get insurance or to be educated. There was a unitary all-or-nothing notion of competence which the legal system had adopted. The legal system, with its rules and principles, tends to lag several years behind professional understanding of new models for delivering services. Even now, some of the modern notions about habilitation, normalization, deinstitutionalization and professional competence are only beginning to work their way into laws and presumptions in the legal system.

laws and
presumptions

Over the last five years or so, two important trends, or movements, have merged. As a consequence, the area of mental retardation law has assumed a great deal more importance to judges, lawyers and to the legal status

community. Mentally retarded persons now have a relatively different legal status than they did before. One movement involved civil rights. The mentally retarded came in as a minority group, and what's happened is that it has been a kind of systematic test case campaign, along with other strategies, to try to articulate and implement the rights of this rather powerless, underrepresented group of people. At the same time, mentally retarded persons, their friends, families and advocates have taken their place in the general consumerism movement that we have seen in other areas, like product-safety, the environment and general health. Mentally retarded persons and their families are now seeing themselves as the consumers of services which should meet certain standards. They are learning to assert their rights to these services rather than seeing these services as something they have to plead or beg for, like an alms-seeker. Services are no longer viewed as something that might be bestowed by the superintendent of a school, or a legislature in its generosity, but that families don't have any legal right to.

right to education

right to treatment

The beginning of this change came in the **right to education** and **right to treatment** areas. In 1971 a very courageous federal judge in Alabama, Frank Johnson, ruled for the first time that persons who are involuntarily confined in Alabama's institutions for the mentally ill and its state institution for the mentally retarded, Partlow State School, had a constitutional right to treatment. And that was the first time a federal, or for that matter a state, court had recognized the constitutional right to treatment. The mental retardation aspect of that case was decided on the theory that persons confined at Partlow State School had been deprived of a basic constitutional right to libery, and the due process clause came into play. The due process clause says that no one shall be deprived of life, liberty or property without due process of law. Of course, the Constitution nowhere speaks directly about the right to treatment, but the right to treatment was constructed out of the due process guarantee. The court then held that residents of the Alabama mental retardation institution system had not committed any crime, were guilty of no anti-social conduct and hadn't even been provided with the usual procedural process safeguards available to persons in the criminal system. To confine them without meaningful programs and services designed to give a realistic opportunity to learn those skills necessary for return to the community would amount to imprisoning them without due process. And, therefore, the court held that there had to be some kind of other purpose of quid pro quo in exchange for the deprivation of liberty. Then a very exciting process began; a process which gave the abstract notion of a right to treatment or habilitation some specific content or meaning. The court held several many-day hearings and experts from major professional and consumer groups, including NARC, AAMD, the American Psychological and American Orthopsychiatric

Associations, came and gave expert testimony. Some of the most powerful testimony, and it was the beginning of my education in this field, came from people like Gunnar Dybwad, Phil Roos and Jim Clements, who had to start from scratch and educate the court by dispelling a lot of myths held by lawyers, judges and other members of the public about mentally retarded persons and what might be done for them. This education process eventually resulted in the court recognizing that with active programming people could be moved out of institutions, back into communities; that their functioning could greatly improve. The court also learned that in a custodial institution, without some positive efforts at programming and an individualized approach, the functioning of the residents would inevitably deteriorate, and they would be harmed.

I remember Gunnar Dybwad explaining to the court how, after touring Partlow State School and reviewing records, he had seen many residents who had known how to walk and had lost their walking skills, or who had known how to talk but had stopped talking. There was no stimulation to encourage learning, and residents lost basic skills instead of learning new ones.

skills

Out of the Alabama case came a whole series of detailed standards in three general areas. The right to treatment was seen as involving an adequate staff representing different training and different skills and in numbers large enough to assure some reasonable likelihood of interaction with all the residents.

standards

A second area had to do with the need for an individualized treatment plan and program for each resident.

Finally, under an umbrella concept--that it wasn't really possible to give adequate habilitation without a humane, psychological and physical environment - the court ordered basic nutritional standards, physical plant standards, the right to privacy, the right to get outside and have exercise certain numbers of hours each day and so forth. These standards have been picked up and modified as appropriate in a number of other cases around the country. The Wyatt case is a prototype or model like other cases in different areas. There are, in process now, maybe 20 right to treatment cases around the country, and we have either consent judgments or court rulings supporting a right to habilitation in a number of states including Massachusetts, New York, Nebraska, Minnesota, Texas and Alabama.

environments

The Wyatt case was followed by a very important case using a slightly different theory in New York. Shortly after Wyatt was decided, legal assistance and civil liberties lawyers in New York, working with the state association for retarded citizens and some individual clients, filed suit in the "Willowbrook" case in New York (New York State Association for Retarded Children v. Carey) and that case has had a different, very significant development. The judge initially was skeptical that mentally retarded children would have a right to habilitation under the Constitution. The reason for this was, he said, "The reality is that as bad as the Willowbrook School may be, there is a waiting list ten years long and parents and their children are queued up. There are really no alternatives; that's why the parents and their children get in line for admission. Now how can we fairly say that these people are being involuntarily deprived of their liberty by the state?" This was a very disappointing initial ruling by the court that came on plaintiff's motion for protective preliminary relief. In most of these cases, to be good test cases, they should be brought where the facts are most striking and where a court can be motivated to take the rather exceptional action of becoming involved and beginning to take up some functions that really the administrative branches or the legislative branches of government should be performing but for some reason aren't. So, in most of these cases there is usually an early motion for preliminary relief which wouldn't be as extensive or complete as the ultimate relief which plaintiffs are seeking from the court but would safeguard the physical safety of residents at the institution while litigation goes on. The plaintiffs came into the Willowbrook case asking for some basic improvement in attendant level staff, the fire safety of the building, etc., and that is when the court said, "I can't give you preliminary relief because I'm not sure you are going to prevail on the merits. And the reason is, it seems to me that these people are really here on a voluntary status."

voluntary status

Fortunately, by the time the case ended a year ago, the court had been convinced otherwise. The case was actually settled with a consent decree that was ratified by the court. A successful strategy was to convince the court that even under a lower standard, a protection from harm standard, the residents here had basic rights and that from a functional point of view the kinds of relief the court would have to order under protection from harm theory would be more or less the same as what other courts had ordered in other places under a right to treatment theory.

protection from harm

What the court said in Willowbrook initially was, "I don't know whether there's a right to treatment, but I do know that when the state agrees to take custody of mentally retarded children then it has to guarantee them at least the same kind of minimal, safe, humane environment we give prisoners. Otherwise, that would be a gross violation of equal protection." At a minimun, institutional residents are entitled to protection from harm, and the strategy used was to again bring in distinguished experts from around the country to convince the court of the fact that if there aren't

equal protection

various kinds of affirmative input and services and staffing ratios there will be deterioration. By the end of the full-scale hearing the court was convinced and was pleased to affirm a very detailed consent judgment that was functionally about the same kind of judgment the court had issued in Alabama under a right to treatment theory.

The Willowbrook case is particularly notable because the right to protection from harm theory applies to all residents regardless of status; regardless of whether they're labeled voluntary admissions or are seen as persons involuntarily committed. Therefore, the potential range of that decision, its impact, is greater.

At the same time, there has been an attempt to convince the court that however voluntary those admissions were from the point of view of the parents, they ought to have the same due process right to treatment as other persons involuntarily committed. The court, in its final order, gave the residents all the relief they would be entitled to under either theory.

due process

Now that's history, and we can talk about some significant current events.

There is a major effort in these institutional cases to neither legitimatize institutions nor to undercut efforts at deinstitutionalization which would provide a full range of services in the community. I was having lunch with someone who asked about this and was very concerned about the effect of these cases--that no matter how well intentioned the people were in bringing them--they would inevitably force state resources to go to institutions to bring them up to minimum standards and therefore take away energy and resources from the efforts to provide treatment in the community.

institutions

At Partlow School there was a number of negligent homicides from drug overdoses because no one watched the medication, deaths by scalding water in the showers, people getting injured in fires, etc., and one had to first try and make these buildings safe because, in reality, people were going to live there for some time. The principle of least restrictive alternative was mentioned in these cases, but it wasn't the focus.

safety

A case was filed almost four years ago in Washington, D.C., called Dixon v. Weinberger which tried to take the right to treatment one step further. That case is about the situation of persons confined at St. Elizabeth's Hospital in Washington, which is mainly a facility for the mentally ill, although there are a number of mentally retarded residents as well. The staff at St. Elizabeth and NIMH conducted a study which suggested that somewhere between 60 and 80 percent of the residents would do better, from an habilitation or therapeutic point of view, in some kind

least restrictive

of less restrictive facility in the community. Those residents have been kept at St. Elizabeth's Hospital because there simply aren't enough programs in the D. C. community to which they could be released and because total release with no followup services ("dumping") would be equally or perhaps more dangerous to the residents than continued confinement at St. Elizabeth's Hospital.

service options

The *Dixon* case was brought under the theory that residents had a right to treatment, which was not limited to treatment in a specific facility, or setting, but included the kinds of services that would be appropriate to each person on an individual basis. If that meant living in a group home or foster home and going to the regular school system, or if it meant living in some kind of a structured apartment situation and going to vocational rehabilitation in the community, or living in the community in an intermediate or skilled nursing home, that's the kind of treatment these persons were legally entitled to.

implementation

In Washington, D. C., there happens to be, as there is in several states, a statute which provides a right to treatment. A court ruling last year broadened this statutory right to treatment to include treatment in a community-based facility, where appropriate. Whether we will ultimately be successful in implementing this decision is still an open question and that is the stickiest part of all of these cases. Lawyers really don't have the special kind of training or expertise to do community organizing and political lobbying and the followup to make some of these very important legal decisions become a reality. For this lawyers have to work with the managers and the consumer groups, and we have to find structures to monitor and enforce implementation. Some structures are being experimented with around the country--things like the human rights committees to review and monitor implementation of Judge Johnson's order in Alabama or Judge Judd's order in Willowbrook. In Washington, D. C., we now have a master to study the school system and recommend basic changes because the D. C. government didn't respond to the requirements of the court's order in the *Mills* right to education case.

right to habilitation

Other recent developments in right to treatment law involve a very good right to habilitation decision in a Minnesota case called *Welsch v. Likins* The decision came down in 1973 and again set staffing ratios, requirements for individualized evaluations and program plans, minimum physical plant conditions, etc. Some of these requirements were complied with, and others, especially the staffing requirements, have not been complied with in the two years since the decree. After giving the state officials ample time to come into conformance, the court took a radical step recently and enjoined all of the hiring and fiscal control statutes court decree

that every state has for instance, "that the Commissioner of Mental Health shall hire no more persons than are allotted by the legislature in any of the following categories, or shall spend money only up to the line amount budgeted for in the most recent budget and only in the categories considered." This is an example of the court taking extreme action to try and enforce its constitutional rights decree by telling administrative officials that they should go ahead and hire and allocate resources above and beyond what the legislature has called for. These statutes are obviously necessary for state administration and not unconstitutional in and of themselves, but they are unconstitutional insofar as they prevent the implementation of a decree that a court shaped after it had found a violation of fundamental constitutional rights. Needless to say, the State of Minnesota hit the ceiling when the court came down with its most recent order, and the legislature has hired a very distinguished professor of law at the University of Chicago to write a brief on its behalf. The State of Minnesota has been joined by about six other state governments in an amicus brief. They are arguing that principles of separation of powers of government, of federalism and of state's sovereign immunity make it illegal for the court to have interfered in the way that it has.

constitutional guarantees

There is also a strong argument on the other side. There's a longstanding tradition in the law that where constitutional rights are being violated the absence of funds is no excuse. The underlying premise here is that whether or not the State of Minnesota, in its wisdom, chooses to run a mental retardation facility is entirely its business, but if the state does choose to operate such a facility, then it must be operated so as to be consistent with the rights guaranteed by the Constitution. Once the court has found that constitutional rights to habilitation and protection from harm have been violated, then the state has to decide either to put in the necessary funds or to go out of the business. So we don't have a situation where the court is really telling a state exactly how to allocate its funds or what to do, although that's the way the state is trying to make it sound in its brief. It's really a situation where the court says whether to do thus and so is up to you, but if you do, then it has to be consistent with minimum constitutional standards.

priorities

This issue has been implicit in all of the cases that have been brought, beginning with Wyatt and the Park cases back in 1971, and it was kind of brilliantly and polemically highlighted by George Dean, lawyer for the plaintiffs, in the Alabama case. This same excuse was coming--"We just don't have the money. We'd like to do better, but we don't have the money to give these people their basic rights," and George Dean researched the budget for the next year. He found that there were appropriations for a livestock coliseum, a football hall of fame and a Miss Alabama pageant, with fairly substantial amounts of money, and a White House of the Confederacy, I think, already appropriated for the State of Alabama for the next year. Then George Dean wrote his pleading and said that he thought his clients "would be better treated in the State of Alabama if they were athletic or photogenic cows of Confederate ancestry."

fiscal priorities

So this Welsch case is on appeal to the Eighth Circuit Court, and we're waiting anxiously to see how the court rules. It will probably go right on up to the Supreme Court either way. The issue is really one of fiscal priorities, how states allocate resources and whether the Constitution places limits on the otherwise free reign of legislatures to decide on funding priorities for welfare, education, highways, wars or habilitation and which are more important and to what degree.

civil commitment

less restrictive alternatives

Now, another case that was argued in the Supreme Court recently relates to these other cases in that better treatment could be given in our residential facilities if all the residents really needed to be there; and one way to do that is to control who gets admitted in the first place. The case I'm referring to is Bartley v. Kremens, and this is the case which challenges the traditional assumption that parents automatically represent the best interests of their children and that parents can voluntarily place their children in institutions without the need for any kind of neutral hearings by some kind of administrative or judicial tribunal to assess the need for that commitment. There have been lower court rulings recently in Tennessee, Pennsylvania and Georgia, all finding that because of the enormous costs involved the physical and psychological pressures on families and the fact that a community doesn't provide ample backup or support, it can't be assumed that when a parent is finally driven to the decision to institutionalize a child that this decision is voluntary on the child's part or in his best interest. In Pennsylvania a three-judge district court has ruled that before a minor can be committed for indefinite institutionalization there be some kind of a basic due process hearing and that the child have a lawyer to represent him in the process; that there be a hearing; that less restrictive alternatives be explored; etc. This decision undermines a very major legal tradition favoring family autonomy in almost all situations. It was kind of foreshadowed by the decisions last term in the abortion cases where the Supreme Court held that children wanting an abortion had a right to some kind of a hearing and there couldn't be an automatic parental veto. The court noted that children had a strong independent interest which must be attended to.

Perhaps this is the beginning of review and reform of our civil commitment process for mentally retarded persons and, coming closely with it, a look at the process by which we classify persons as mentally retarded and also the process by which we give mentally retarded persons guardians and think about their incompetency.

labels

Just very briefly, what seems to be happening here is a rethinking in the law of the way things have operated for some time. We are beginning to realize, for instance, that classification has very important consequences for mentally retarded persons. First of all, to be labeled mentally retarded still brings a lot of stigma and a whole series of self-fulfilling prophecies which can have a very negative impact on the person given that label. These individuals are frequently stigmatized as in some way inferior. Labels tend to put such value on intellectual and verbal skills that an assumption is generated that people labeled "mentally retarded" aren't really human like the rest of us. There has been a lot of good work done in attacking this stereotype and in changing public attitudes. There have been some interesting studies recently showing attitudes in the employment sector by co-workers towards mentally retarded workers. Where there used to be an incredible amount of prejudice towards mentally retarded workers, the recent Gallup study done for PCMR shows that these attitudes are changing. But still, there is a lot of prejudice, and even apart from the stigma of the label, it's just a fact that very important consequences, both positive and negative, follow from the classification as "mentally retarded." One might have the right to special education, for instance, or special services or programs, but, on the other hand, one might be denied licenses or insurance.

classification

Beginning in the area of education, we've gotten decisions which say this classification is so important we have to have due process both in terms of fair substance of standards and in terms of procedures to make sure the label is applied correctly. There have been several school cases, one called Larry P. v. Riles, challenging the classification of persons from minority racial or ethnic groups as mentally retarded on the grounds that the tests are culturally or racially biased. Now, in the federal Education for All Handicapped Children Act we have standards that were ordered earlier in the Park case and in the Mills case - to ensure that before persons are labeled mentally retarded and before decisions about placement following from those labels are made, there be minimum due process procedural protections, like a right to notice that the classification decision is coming up, to be present, to have an advocate to assist you if you wish, to question the label or the placement, etc.

competency

Closely related to this are some very interesting decisions attacking the notion of unitary competency that is, the notion that mentally retarded persons are either competent to do everything or competent to do nothing, and also attacking the notion that just because a person has been in an institution he is automatically incompetent. That's a notion which has existed in the law and is patently ridiculous. A lot of mentally retarded persons do, for instance, voluntarily admit themselves to institutions, but in many states, as a matter of law, anyone who has been in a state institution loses all of his basic rights and privileges as a citizen and is considered incompetent unless there is a special judicial hearing to reverse that status. What's now beginning to evolve in the law is the notion that a person might not be competent to handle detailed monetary affairs but might be perfectly competent to make personal decisions even about such things as marrying or having a family, voting or driving.

guardianship

With this is coming a whole different system of guardianship that tries to give a person a guardianship tailored to his individual needs. A person who is moderately retarded but needs some assistance will not lose any rights by being declared incompetent. He could be given some kind of advocate service he can rely on or could have an ombudsman he can go to or perhaps a facilitative guardianship which provides an advisor if the retarded person wants it but not a guardian of the person and estate who will have full power to act on behalf of the mentally retarded individual.

Just as the right to education in the public schools, or placement in a community facility, is a less restrictive alternative to institutionalization, so, too, is having a limited guardian less restrictive and allows for the opportunity to exercise autonomy as fully as is possible.

Now there is a lot to say about rights in the community, but I'm going to conclude because I know time's up. Let me end with zoning, which I gather is an issue of some importance to this group.

zoning

After beginning with the extreme cases of abuse of mentally retarded persons in institutions, the trend now has been to focus on the more subtle and pervasive, perhaps even more important, issues of the rights of these people to be full citizens in the community. One of the crucial areas has to do with zoning.

There was a Supreme Court decision a couple of years ago in a case called Belle Terre which seemed to be very ominous for mentally retarded persons. This was a case in which a group of college students, unrelated by blood, tried to form a functional family, a commune, in an area that had been zoned for single family residential zones. The Supreme Court upheld the right of the local community to zone as it wishes and said that this group didn't meet the requirements for being in a single family residential zone and that they couldn't live there. At the time the court's language seemed very ominous in terms of the right of mentally retarded persons to live in a group home or foster home in communities, but I am happy to report that there's been a spate of cases in the last year which seem to be upholding the rights of retarded individuals to live in family-like situations in the community. There was a very good case recently in New York which is called Little Neck Community Association

v. Working Organization for Retarded Children. There was also a good decision called Anderson v. City of Shoreview a little while back in Minnesota. There's been another important decision in Los Angeles. Taking the New York case as a prototype, the community, in trying to reject the mentally retarded persons, made the argument that only families related by blood were allowed. The court rejected the argument, and it was affirmed on appeal within the state court system. There was a state policy, as is the case in many states, that normalization and deinstitutionalization were to be fostered and that mentally retarded persons were to be accepted as full citizens in the community. The court held that it would violate state policy and constitutional rights for local zoning ordinances to be used to keep such persons out of the community, and although it was reasonable to have areas that were zoned for families, it was important to look at the family functionally. So long as there was a sense of stability and continuity, regardless of whether the persons in this group home were related by blood ties or not, they had a right to be in this single family residential zone.

functional
families

I haven't begun to be able to cover everything. I have been trying to give an overview of the legal rights movement. Although a lot of the early cases began in the institutional area, the focus of attention and energy has clearly shifted to the issue of how mentally retarded persons can function and be protected as citizens in the community. The legal effort should dovetail very nicely with the efforts of other planners and persons trying to promote deinstitutionalization.

Editor's Note: Mr. Friedman has just finished an inexpensive and quite comprehensive paperback entitled An American Civil Liberties Union Handbook: The Rights of Mentally Retarded Persons which is published by Avon Books and is available both at local stores and through Avon Books, Mail Order Department, 250 W. 55th Street, New York, New York 10019, at the price of $1.50 plus 25 cents per copy for mailing. This book covers the full scope of the rights of mentally retarded persons, including an introduction, and major sections on the problems of classification, overview of civil commitment, competency and guardianship proceedings; rights of mentally retarded persons in institutions; rights of mentally retarded persons in the community; rights of mentally retarded persons in the criminal process; and the right to a legal advocate, plus a select glossary, select bibliography, list of resource organizations and other appendices.

Accountability and Monitoring

ED SKARNULIS

"Watch what we do, not what we say." John Mitchell, former U.S. Attorney General, 1969.

INTRODUCTION:

Eleanor Elkin's historical review vividly portrays the frustration of parents in trying to unlock the doors of institution snakepits in the 1950's. She relates how difficult it was to get information and how all of you worked alone or in small groups. How nice it would be if the efforts of those early years had brought an end to the exploitation and abuse of mentally retarded persons.

But Willowbrook, Partlow, Johns Hopkins Hospital, Sunland and other horror stories of the 70's remind us that two and one-half decades of work didn't end blatant abuse and neglect. In fact, with the advent of public support and awareness a different set of problems has emerged.

New resources provided by enlightened government representatives have spawned a breed of service providers who must charitably be called mercenaries. Unctuous, glib, smooth talking--they prey on families who have had no help before and are willing to place themselves in the protective hands of charlatans offering relief, however inappropriate.

Tired, burned-out ARC members who got part of what they fought for have become more concerned with preserving what they've got than pushing for more. This makes recruitment for monitoring committees difficult. It, on occasion, even results in one group of parents actually defending dehumanizing conditions and incompetent service providers against another group who are trying to upgrade those conditions and remove those providers.

We're not alone. These are logical outcomes reminiscent of the mental health, civil rights, "War on Poverty," and other human rights movements. They tell us that monitoring is still terribly important and that we need a more mature parent organization with a permanent commitment to Robert Frost's Stopping by the Woods on a Snowy Evening: "But I have promises to keep. And miles to go before I sleep, and miles to go before I sleep."

WHAT IS MONITORING?

to watch, observe or check

Three words will appear frequently in this paper. The word "monitoring" simply means "to watch, observe or check." Someone acts as an overseer who warns when a job isn't done or isn't done right and instructs on how to do it the way it should be done. Note the dual task of both warning and instructing. The second word is "responsibility," by which we mean "...liable to be called upon to answer as the primary cause, motive or agent..." (Webster's). Third, "accountability" refers to the one answerable for a job not being done, the place where the buck stops.

accountability

Thus, when we monitor (watch, warn and instruct), we're concerned with identifying who is responsible for doing something or seeing it gets done and knowing if it isn't done who will ultimately be held accountable. Remember that a ward aide may be responsible for doing a job but may not be the one to hold accountable if it either isn't done or isn't done right. That may have to be the superintendent or director.

REPRESENTATIVES IN THE PROCESS:

network

The most difficult part of monitoring is the need to focus energy where it will do the most good. For example, it would be wasteful if every local unit of NARC attempted to set up a lobby in Washington, D.C., to influence legislation at that level. Instead, each local Association could serve on a network when NARC's Washington office needs people to contact individual congressmen and senators (which is, we hope, exactly how the system of ARC units operates). The following are some approaches to monitoring that have been used:

A. Level of Power

   1. Local
   2. State
   3. National

B. Population Served

1. Private organizations
2. Public

C. Location in Hierarchy

1. Internal monitoring, e.g., as a board member
2. External monitoring, e.g., as a consumer looking in

D. Authority for Monitoring

1. Standard Setting, voluntary, (AC/MR-DD,[1] PASS [2])
2. Standard Setting, legal or involuntary, (Health Dept., Welfare, Licensing, Zoning)

This paper looks at monitoring as a "vested interest." Consumers, the people who pay (funders) and the people who serve (service providers) have something to gain by good monitoring. Whether one is employed in an agency, receives services from the agency or is the benefactor who pays the bills, a person can monitor. Too often we approach this subject solely from the point of view of the consumer watching, warning and instructing the service provider. The consumers are depicted as noble souls and the program employees as devious miscreants. No one has a monopoly on morally correct behavior. Many residential aides, nurses and administrators have been outspoken advocates for mentally retarded citizens, risking their jobs to bring problems to the attention of authorities or parents.

vested interest

More and more service providers are willing to look at themselves and invite others in to do the same. Often it is a person in the system that exposes a bad situation. Dismantling institutions may be facilitated more by progressive superintendents than by demands for reform from the outside. (The Macomb-Oakland, Michigan experience is a good example.)

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[1] Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities. Chicago, Illinois: Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, Joint Commission on Accreditation of Hospitals, 1975.

[2] Wolfensberger, W. & Glenn, L. PASS III. Program Analysis of Service Systems. A Method for the Quantitive Evaluation of Human Services. Field Manual and Handbook. Toronto, Canada: National Institute on Mental Retardation, 1973.

consumers

The people most concerned with monitoring should be the consumers of the service. Consumers include mentally retarded persons, the "primary" consumers, or his parents who also receive services but are "secondary" consumers since the help given them is almost always a way to help the retarded adult or child. We should include in this category consumer representatives, such as courts, citizen advocates, ARCs, etc. They're also concerned that the interests of a mentally retarded citizen are safeguarded.

cost effective

In an era of "taxpayer's revolt" it would be naive to ignore the public and private funding groups who increasingly want to participate in monitoring. These are not our adversaries (although they may have been viewed that way), but partners. Wouldn't it be interesting to see the reactions of people if our press releases took a new approach, devoid of the predictable demand for more funds for more services? We could join with people who provide financial support for our programs to move beyond quality to fiscal issues as well. Are schools that put all handicapped kids into special education cost-effective? Can we afford two separate systems, institution and community-based? Who is responsible for redirecting funds appropriated by Congress away from deinstitutionalization toward bigger and better institutions? Do monolithic agencies established to serve several disability groups achieve that goal? (Many times we find programs helping one group at the expense of another.) Is Developmental Disabilities working? Why or why not?

Private funding sources, such as United Way, need to be told how effectively their money is being used. Far better for us as consumer representatives to lead the way in analyses than for them to make assessments based on incomplete data.

responsibilities

It is easy to monitor agencies that have clear-cut responsibilities. For example, one agency, in a defined geographic area and clearly designated as accountable for all mentally retarded citizens of that area, can develop a system and be accountable for:

- coordinating their own or other agency services;
- monitoring their own and other agency services;
- backup or filling gaps.

This is usually not the case, however, and many agencies may share in serving mentally retarded persons. Generic agencies like the "Y," Boy Scouts and others need much help to understand how to be most effective. Once educated they can become very skilled at overseeing their own operations.

"HOW TO" FOR CONSUMERS:

What follows is a simple listing of ways that consumers, funders and service providers can monitor themselves or others. Some safeguards should be mentioned. Please don't deny service providers the same rights you safeguard for mentally retarded persons. Monitoring need not be an adversary procedure. You'll get far more cooperation from people if you begin by assuming good intentions rather than evil. Often the "watchdog" approach to monitoring degenerates into a Machiavellian approach with the rights of providers trampled on to help mentally retarded persons. Surely it is naive to believe that we ever gained rights for consumers by denying them to others. It does matter that a residential employee has inadequate funds to do the job properly. It is important that in a public condemnation of a decrepit residential program credit be given to those who tried to change it. Assertiveness, yes. Incisive questioning, yes. Seeing before believing, yes. Facts and documentation, yes. But subjugation of one group for the sake of another, no.

safeguards

Thus, carefully select your committee members. Be sure they know whose needs are to be met by their work on the committee; those of the mentally retarded, not their own.

A. Be in a position to influence others.

   1. Form agency boards/advisory committees.
   2. Represent your agency in standard setting groups; e.g., United Community Service, D.D. Councils, etc.
   3. Insist on written contracts for services provided. This should include agreement on the nature and quality of services.
   4. Participate in established grievance procedures or propose them if they don't exist.
   5. Gain representation at all levels. For example, an ARC member at every facility or on a program advisory committee could help ensure good programs.

B. Ad Hoc Participation.

   1. Legislative hearings, City Council meetings, County Board meetings.
   2. President's (Governor's, Mayor's) Committee on Handicapped.
   3. United Way Fund Committees

4. Title XX Public Hearings.
5. Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MR-DD) public meetings -- Developmental Disabilities Group.

C. Establish Ombudsperson positions.

D. Ensure distribution of volunteer forces through:

1. Specialization (somebody with skills in finance, residential services, education, etc.)
2. Division of labor. People at national levels (NARC) influencing Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, Developmental Disabilities, federal legislators at that level; state ARCs at the next level; and your local ARC at point of service.

resistance

Traditionally consumers who monitor are viewed as "troublemakers" or people who look only for problems. This leads to resistance by those being monitored. If this resistance is innocent, your positive comments about what you see that is good should serve to reduce the barriers. If it is resistance designed to hide intolerable conditions, the booklet by Bogdan, Observing in Institutions, should be helpful. [3]

simplistic view

One last comment on residential monitoring by consumers. Residential services are often viewed as the most simple to provide. After all, "everyone lives in a home." This simplistic view may get you into trouble. It's easy to look at the cleanliness of the residence and not the way people relate to each other. Parent complaints about missing socks in the laundry take on exaggerated importance, and the quality of social life becomes diminished. The temptation to recommend bulk food purchase and turning off lights to save money becomes irresistable, but often ignores realities like the exposure of residents to community by buying at the local grocery store or the insignificant percentage of costs saved through such efforts (personnel almost always accounts for 75% or more of the costs). Encouraging providers to go pick up a donated pool table may be unrealistic in view of inadequate staffing levels.

"HOW TO" FOR FUNDING SOURCES:

Whoever pays the bills commands a lot of power. You have a right (and responsibility) to know why a service is provided, how much it costs, who does what to whom, when, where, how and why. Your tools include policy making authority on boards, authority to hire or fire the executive officer and clear lines of authority and responsibility. This can be done through:

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[3] Bogdan, R. Observing in Institutions. Syracuse, New York: Human Policy Press, Syracuse University.

program audit

1. Fiscal, administrative and program audits both scheduled and impromptu.
    a. External - Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, PASS, FUNDET, consultants hired by board.
    b. Internal - Auditor reporting to board, representation on program advisory committees, membership in local ARC.
2. Hiring of an ombudsperson or legal advocate.
3. Consumer group liaisons (consumers on board, appeal procedures).
4. Becoming a tour guide for the agency.
5. Insisting on regular board meetings.
6. Getting rid of "dead weight" on board. Put inactive members on honorary boards.
7. Watching out for accountants who don't take vacations.

"HOW TO" FOR SERVICE PROVIDERS:

visibility

Be visable and undefended. Remember that consumers can help you to accomplish goals you can't otherwise accomplish. They can speak out without fear of recrimination. They may have great influence with funding sources, particularly public. When program staff make mistakes, as they will, knowledgeable consumers can put errors into perspective for the news media or for other parents. To accomplish an open service system requires:

A. Consumer participation (both clients and parents).
    1. Individual written contracts for services to be provided.
    2. Facility or program advisory councils.
    3. Area, department or division administration advisory councils.
    4. Agency or executive level administration advisory councils.
    5. Governing board membership and advisory councils.

B. Encouraging external monitoring.
    1. University practicum students.
    2. Volunteer involvement, including ARC liaisons.

3. Citizen advocates.
4. AC/MR-DD, PASS, FUNDET, etc.

C. Mandated internal monitoring.

1. Visits to residences by all levels of administration.
2. Client/parent grievance procedures.
3. Internal affairs committee to review allegations of misconduct by staff and make recommendations to management.
4. Built in safeguards against abuse or neglect, e.g., staff rotation, regular personnel evaluations, mandatory training, personnel exchanges with other agencies, mandated vacations and relief to prevent burnout of staff.

D. Meeting legal requirements.

1. City inspections - zoning, health, fire.
2. Welfare licensing, health department regulations.
3. State mental retardation office regulations.
4. Local, state protective services regulations.

SUMMARY:

ARCs have historically advocated for the rights of all mentally retarded citizens.[4] Sometimes they met resistance from the service providers or had to fight to obtain funds for needed services. The funding sources have not always responded kindly to such efforts.

natural tension

This paper has tried to illustrate that natural tension which exists among service providers, funders and consumer groups may be either beneficial or pathological. As long as all groups agree to focus on mentally retarded persons, we'll stumble through our differences and work together. This is called looking at the product rather than the process. A few years ago I watched a courageous group of counselors, vocational and residential employees try to get their administrators to stop an employee from physically abusing the clients in his residence. The administrators astonished these advocates by refusing to intervene. The reason? The administrators were piqued because their fellow supervisor (whose responsibility it was to monitor and prevent such abuse) was publicly

abuse

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[4] Residential Services: Position Statements of the National Association for Retarded Citizens. Arlington, Texas: National Association for Retarded Citizens, October 1976.

embarrassed by the group's revelations. They were more concerned with process than product.

As consumers, providers and funders let's join together to keep each other honest.

Public Institutions

Elisabeth Ludeman Developmental Center

GEORGE F. GARLAND

The Elisabeth Ludeman Developmental Center is part of the Illinois Department of Mental Health & Developmental Disabilities and is accredited by the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MR-DD) of the Joint Commission on Accreditation of Hospitals.

METHODS AND CRITERIA USED TO DETERMINE INDIVIDUAL NEED FOR ADMISSION:

During the past several years the system for admitting a client to a state residential facility in Illinois has gone through considerable change. In the early 1960's referrals were made through many avenues directly to the state facility. During this time there were lengthy waiting lists and a three to four year waiting period before residential services could be offered to the client in need. However, this was partially due to the fact that there were only two state-operated residential facilities for the mentally retarded in Illinois and very few community based programs.

In the late 1960's the Department of Mental Health adopted a "zone concept." The state was divided into eight geographic zones. Each zone was administered by a zone director and had the responsibility of seeing that appropriate services were provided to clients in need within the designated geographic areas. Introduced within the zone concept was the beginning of a "case manager" system. This permitted referrals for services to be made to the zone director. The referral information was then passed on to the general office, where a central waiting list was established for each of the facilities providing residential services to the mentally

zone
concept

regions

retarded and mentally ill in Illinois. The case manager within each zone would attempt to discuss the individual needs of the client with appropriate personnel and family members to determine the best programs available within that zone prior to making a referral to a state residential facility. In the early 1970's the State of Illinois was reorganized into seven regions. The regional organization was a modification of the "zone concept"; an added feature of the "region organization" was that all state agencies would recognize the same boundaries in providing services. For the most part, this has been done, which allows agencies to work more effectively together in providing services to clients.

The Chicago Metropolitan Area is one service region, subdivided into nine subregions, each of which serves a specific geographic area. Each subregion has services for both mentally retarded and mentally ill, which provide for better monitoring and followup of services.

Another aspect of the region organization was the designation of an individual within each region whose responsibility was to see that services were provided to the developmentally disabled. This has helped a great deal in pinpointing specific service needs in each region.

referral agency

During this time, in the Chicago area, a central referral agency was adopted, this being the Illinois State Pediatric Institute which is now the Illinois Institute for Developmental Disabilities. This facility would screen and complete comprehensive evaluations on prospective clients needing service in the Chicago area.

After the initial screening, the Institute would then contact the appropriate state facility for possible admission. It was soon recognized, however, that it was becoming increasingly difficult for a single referral agency to operate effectively. This facility was having difficulty in handling the large case load and was not able to effectively utilize the number of community services which were available throughout the Chicago Metropolitan Area.

purchase of care

In 1973 the Department of Mental Health was able to abolish its waiting list for admission to state-operated residential facilities. This was due to the building of new facilities throughout the state, increased community programs and additional funding appropriated for individual care grants which allowed the Department to purchase care outside of state-operated facilities.

In early 1975 the Chicago Region also began using a case manager system. Within this system clients are referred for services to the case manager within the subregion. One of the specific responsibilities of the case manager is to begin to deal effectively with the parents and to find the least restrictive environment possible to provide the needed services to the client. If it is felt that services needed can best be provided in a state facility, the case manager then contacts the Coordinator of Placement for the region who passes on the referral information to the appropriate residential care facility. Upon receipt of the client referral at the facility, staff will meet to review the referral and begin to determine appropriateness for admission.

The next step is to set up a pre-admission staffing. This staffing includes parents, a representative from the appropriate subregion and an interdisciplinary team from the unit in which the client will reside. This interdisciplinary team includes a physician, a nurse, a psychologist, an activity therapist, a behavior specialist, mental health technicians and any other appropriate personnel, depending on the individual needs of the client. At the pre-admission staffing the final decision is made as to whether or not the client does need admission, and initial plans are made for an individual habilitation program. Also established at this staffing is the beginning of a very close working relationship between the staff, the parent(s) and the client.

staffing

THE DEVELOPMENT OF INDIVIDUAL PROGRAM PLANS:

Before describing methods and procedures of developing individual habilitation plans for residents at Ludeman, I would like to take a minute to generally describe the organizational structure of the Center. The Center is administered by a Superintendent, with the assistance of an Executive Committee which consists of all the top management personnel. The facility operates within a "unit system" and is divided into five administrative units, each functioning under the direction of a Unit Administrator (who is a member of the Executive Committee). The unit is the base of operation, each unit being comprised of ten homes, eight residents to a home, one neighborhood house and approximately 120 staff who provide direct care, home management and specialized services to the residents who reside in the unit. Approximately 96 staff members are mental health technicians whose responsibility it is to work directly in the homes with the residents 24 hours a day, seven days a week. The remaining staff members are from a variety of disciplines and each unit typically has a physician, educators, speech therapist, nurses, psychologists, activity therapists, social worker, a self-care specialist and a program coordinator who is primarily responsible for seeing that effective programs are developed and implemented. Also, within each unit is a supervisor for each of the homes.

unit system

teams

Now let us talk about the development of individual habilitation plans and begin with following a client who has had a pre-admission staffing, and the decision has been reached that admission to the Center should take place.

Within 72 hours after a resident is admitted a post-admission staffing is held, at which an initial treatment plan is prepared.

Within 14 days after the implementation of the initial treatment plan, a more detailed staffing is held and a revised plan is entered in the resident's record, in keeping with the AC/MR-DD Accreditation Standards and Illinois Department of Mental Health and Developmental Disability rules.

evaluation

At this time all services within the unit are represented and a summary of their evaluations concerning the resident is presented. For example: a psychological evaluation - a hearing evaluation - a speech evaluation - a physical therapy evaluation - an educational evaluation - etc. are presented. From these evaluations and a discussion with the home staff and the parent an initial treatment plan is developed.

goal setting

During these staffings, short-term and initial long-range goals are set for the resident by the interdisciplinary team, which includes the parent(s). The team determines the basic needs of the resident and prioritizes these needs. This is a very important part of developing an individual program for each resident. The interdisciplinary team must focus on identifying the developmental needs of the resident and devising ways to meet them. Participating team members share all information and recommendations so a unified and integrated habilitation program plan is developed. This allows the staff to look at the resident as a total person and also allows all staff to work towards the same end with each resident.

monthly review

Following these staffings, all programs on each resident are reviewed at least once every 30 days in a Monthly Review which is conducted very similarly to the post-admission staffing. Various staff members are involved in accordance with the individual needs of the resident and the programs which are currently being implemented. Parents and other involved relatives or guardians are invited to attend each Monthly Review, as well as the representative from the subregion, if programmatically indicated.

program modification

During this Monthly Review each current program in which the resident has been involved is reviewed and progress noted. Problems are discussed and treatment programs recommended. Additional goals are established, or present programs may be deleted or modified, either because they have not been successful or because staff has succeeded in accomplishing the goals.

In addition to the Monthly Review, an Annual Staffing is held for each resident. During the Annual Staffing the entire interdisciplinary team must be present. This team includes the parents and/or guardian and the subregion staff representatives. During this staffing long-range goals are reviewed and objectives set for the coming 12 months. The evaluation of these programs in regard to their success, failure, need for modification and so forth, can be done in a variety of ways. Some of the more traditional means of evaluation, such as comprehensive educational evaluations, speech and hearing evaluations, psychological evaluations, etc. are completed for each resident and are usually presented at the formulation of the initial treatment plan and the Annual Staffing. This gives staff updated information concerning individual programs.

individual programs

However, in addition to the more traditional means of evaluating a program, the individual training programs are reviewed at each Monthly Review. During these Monthly Reviews the data can be evaluated by staff present and discussions take place to determine success of the program and the prognosis for the resident who is participating in that program. It is felt that this is a very important part of the continuation of the evaluation process. Should there be need for program modification or change, this can be initiated and followed through as a result of the Monthly Review.

If new programs are indicated the new programs are then designed by the specialist in the appropriate disciplines working within the unit, in cooperation with the home supervisor and the mental health technicians who work directly with the resident. In further aiding the staff in the development of individual programs, a program format development sheet is used. This takes into consideration relevant aspects of developing and reviewing a program which tells at a glance what the specific goals are.

At the Center other means of reviewing specialized programs or evaluating program outcomes are also utilized before they are individually implemented. This is done through review by various committees such as a Human Rights Committee and a Utilization Review Committee. Ludeman has a very active Human Rights Committee. It meets twice each month and is involved in the process of previewing any specialized behavior management programs recommended for the residents. The committee consists of four staff members from the facility and four parents. It is the unit staff's responsibility to present the specialized program before the Human Rights Committee which then reviews it to ensure that all rights of the resident involved are protected and offers suggestions to the unit staff before the program is implemented. The Human Rights Committee is used as an advisory committee to the Superintendent and to the unit staff concerning the appropriateness of specialized treatment programs and procedures.

human rights

utilization review

The Utilization Review Committee functions to evaluate each unit's effectiveness in providing adequate services and appropriate programs, according to the needs of each resident. This committee looks at the total needs of the resident and ensures that recommended habilitative procedures are being implemented. If a program is going to succeed, it must be supported by the interdisciplinary team. Additionally, the daily implementation of each resident's program by the Mental Health Technicians is critical and must be consistent to ensure the successful development of each resident.

home-like setting

Programs are carried out within each unit and/or within the individual home where the resident lives. A homelike setting is beneficial in developing normalized programs which include the development of appropriate behaviors, self-care skills and social development. This is not to say, however, that the residents are not involved in specialized programs; in fact, most of the residents in each unit are in some type of a special education program each day - an activity program - a speech program - or other types of specialized programs, depending on the individual needs of the resident.

accredited

Ludeman, upon being surveyed by the Accreditation Council, has been accredited for the past two years and, upon a recent resurvey, was reaccredited for an additional two years.

Now that the resident has been taken through the various stages of program development, let us take a look at a typical day at Ludeman and some of the programs in which a resident is involved.

AN OVERVIEW OF VARIOUS SERVICE COMPONENTS ASSOCIATED WITH THE CENTER, ALSO DIFFERENTIATING BETWEEN THOSE SERVICES PROVIDED THROUGH OTHER SERVICES:

community plans

When the Ludeman Center was constructed, it was constructed totally as a subdivision to become an integral part of a south suburban community of metropolitan Chicago. Park Forest is a progressive village of more than 30,000 people. When the State of Illinois Department of Mental Health decided it would like to build a facility in the Park Forest area, representatives approached the village trustees concerning available land. As a result of these negotiations, the village agreed to welcome a state facility for the mentally retarded in the center of their community. The trustees were impressed with the architectural drawings and the overall program plans that had been developed for the Center and felt this Center would blend nicely into their community.

The Center does not have a power plant or central dietary complex, as exist in most traditional state facilities. These types of considerations were well planned prior to its construction. As the facility was developed as a subdivision, each home or living unit is totally self-sufficient. Each home is supplied with gas and electricity from public utilities and receives its own electric and gas bills.

food service

The food service is contractual and food is provided to each home, much in the same style you would receive while taking a lengthy airplane flight. The food is delivered daily in portion controlled packages and is then reconstituted and served family style in each home. Technicians are able to eat with the residents, allowing for training and modeling to assist in developing good eating habits.

pharmacy service

The Center also contracts for pharmacy services. This allows for an individual unit dose prescription for each resident. No prescription at the facility may be written for more than 30 days. This ensures that all prescriptions written for the resident must be reviewed by a physician and, in some cases, the interdisciplinary team, at least once every 30 days. This system has helped in solving various medication problems so many facilities sometimes encounter.

housekeeping

Additionally, the Center does not have central housekeeping staff, and therefore, must contract for its housekeeping service. The housekeeping contract provides daily cleaning services for the large administrative buildings and a service to each home once each four months. This service is a very thorough cleaning, such as stripping and waxing the floors, washing the walls, etc. which is in addition to the regular routine cleaning which is done daily by the technicians.

clothing

Another major and innovative step in providing services to the residents is that each resident who is capable is taken downtown to shop so as to help select his or her own clothing. Clothes are purchased in the same manner you would purchase your own. This allows residents to be dressed much more appropriately and in current styles.

Also, since laundry is done in each home, this allows the staff and residents to take better care of and keep better track of the clothes.

medical service

The Center does not have a hospital or a medical/surgical building. There is, however, a ten-bed Health Center, which provides basic first aid measures and short-term convalescence for common illnesses and injuries. Beyond that, the resident is transported to a local community hospital for treatment, which helps assure the residents of receiving the highest quality medical and nursing care.

Additionally, since the facility is located over 60 acres of ground, there is an enormous job of providing adequate grounds maintenance. The Center has found this service can best be contracted for and, therefore, the grounds maintenance, lawn care and snow removal is handled by a contractor.

security

The village of Park Forest also plays an important part in providing direct and indirect services to the Center, its staff and residents. Some of the security is provided by the police department of the village of Park Forest. As the Center is part of the village, the police do patrol the streets, providing security as they do any other area of the village. However, for hours throughout the night and in the early morning, a contractual agreement was established with a security agency which affords the residents and staff even more protection during these hours.

fire safety

The village also provides the Center with an excellent fire protection program. The Center fire alarms are hooked directly into the Park Forest system and should assistance be needed from the fire department, they can be at any location within the Center within approximately three minutes after the alarm has been sounded. The fire department has continually assisted us in training staff in proper fire prevention methods and in surveying the buildings to make sure we are meeting the necessary fire codes.

Additionally, the fire department provides the Center with a paramedic program. The ambulance can also be at any location within the Center within approximately three minutes to transport a resident to a local community hospital, if needed.

foster grandparents

Another program and service provided to the Center and its residents is the Foster Grandparent Program. This program, totally funded by the Federal Government, provides a service that benefits many of the residents individually. At the present time foster grandparents' services are provided from two surrounding counties - Cook County, which encompasses the Chicago area, and Will County, just south of Cook.

The Center also provides for religious education experiences through contractual services. This service is called SPRED, which stands for Special Religous Education. This is a division of the religous education program of the Archdiocese of Chicago. SPRED utilizes only volunteers - is interdenominational - and attempts to prepare residents to be able to attend appropriate religous services within the surrounding community.

public school

Due to the enactment of public school legislation relating to special education, many of the Center's residents are attending schools within the surrounding communities.

The Center provides needed central or specialized services to the residents. These include: physical therapy, dental, tonsorial, audiology and a large supportive role from our engineering service. Even though the Center has contractual agreements for glass replacement, plumbing, carpentry, etc., it is Engineering's responsibility to see that the homes operate efficiently on a day-to-day basis. Therefore, all minor repairs and modifications are handled by Engineering.

Another integral service provided is staff training and development. All staff working in the direct care area must complete an extensive training program before being assigned to work directly with the residents. This includes 120 classroom hours and 400 hours of on-the-job training. This type of training is required as personnel advance or receive promotions while working at the Center. This extensive training helps to assure that the residents are receiving quality care, training and education from the staff. Many instructors utilized also work directly in the unit, which allows them to have first-hand information and teach from current experiences as well as theory.

staff
development

As has been explained, the Center does have a variety of contractual services and must rely heavily on the community around it. It is felt that by utilizing these types of contractual services the Center is able to operate more efficiently. It allows for a more effective management of affairs in the direct care areas; in other words, those areas providing direct care to the residents. Because of this, approximately 85% of the staff is assigned within the five programmatic units. Contracts are bid annually on a competitive basis and have an option renewal for one year if all aspects of the contract remain the same.

THE SOURCES OF FUNDING

The Elisabeth Ludeman Developmental Center is a state-operated facility; therefore, the budget is totally dependent upon State of Illinois tax money. However, the Center does receive some funds through federal grants - these being Title I, Special Education Programs - The Comprehensive Employment and Training Act, as well as the Association of Rehabilitation Facilities, which provides additional funds for staff training and development.

The Elisabeth Ludeman Developmental Center was recently certified as an intermediate care facility for the developmentally disabled by the Illinois Department of Public Health. As a result of this certification the Department of Mental Health and Developmental Disabilities will be receiving matching funds through Title XIX of the Social Security Act from the Federal Department of Health, Education and Welfare.

ICF/MR

In Illinois the Department of Public Aid is the monitoring agency, and to receive certification the facility must meet the standards for licensure of intermediate care facilities and have a licensed nursing home administrator on the staff.

As of this time, it is undetermined how much the exact yearly reimbursement will be as a result of Ludeman's certification.

surveys

In regard to strategies related to program development and assessment, it is recommended that you request to participate in either the AC/MR-DD Accreditation survey or the Intermediate Care Facility Certification survey, or both. Just participating in these two surveys gives and provides each facility a tremendous amount of insight into quality of programs and overall services being presented to the residents. This provides a more objective viewing of programs and services and provides you with invaluable information as to where, when and how services and personnel need to be upgraded and added. Therefore, it is recommended that even if it is felt accreditation and/or certification standards cannot be totally met, a survey should be requested.

THE RELEVANCY OF FEDERAL, STATE AND LOCAL LAWS, REGULATIONS AND ORDINANCES AND CODES UPON THE OPERATION OF THE FACILITY:

regulations

The establishment of local, state and federal laws, regulations and codes had the most impact prior to the construction and implementation of the Ludeman Center. The facility was built with the intent of becoming accredited and providing the highest quality programs and services possible to the retarded. The impact of these regulations and codes has been positive and helpful in maintaining a most unique physical plant and for the Center to continue to be able to provide quality services and programs to the residents. Certainly those rules and regulations affecting the Center the most are our own Mental Health Codes and Department of Mental Health and Developmental Disabilities rules and regulations; right-to-treatment suits issued in Cook County; the AC/MR-DD Standards; Minimum Standards, Rules and Regulations for Licensure of Intermediate Care Facilities for the Developmentally Disabled; public school legislation; and state and national fire codes.

To summarize the history and development of the Ludeman Center and its programs, a slide presentation will conclude my part of the program.

Following the question and answers session, there are handouts for your information which include the Monthly Review format, the Annual Staffing format and the Program Development format.

Group Homes

Pennsylvania Department of Public Welfare

MEL KNOWLTON

The Pennsylvania Office of Mental Retardation has considered various alternatives for providing the mentally retarded citizens of Pennsylvania with living situations that will enable each individual to reach his or her maximum social and developmental potential. With this goal in mind, the following is an outline of the residential priorities of the Office of Mental Retardation:

Priority I - Support Services Necessary to Keep a Child at Home with Parents or Adults Living Independently:

1. Public Education, pre-school training, vocational training;
2. Family training and education;
3. Family relief or respite care;
4. Homemaker services -
    - Babysitters,
    - Family aides,
    - Homemakers;
5. Visiting nurse services;
6. In-home support (developmental training);
7. Transportation;
8. Leisure time activities;
9. State or federal financial subsidy to parents.

family
resource
services

The Office of Mental Retardation funds all the preceding support services, except for numbers 1 and 9, through a program called Family Resource Services. The development of these programs is based on priorities set by the counties and contingent on the availability of funds.

County priorities and funding availability determine the extent to which each support service category is developed.

Priority II - Adoptive and Foster Homes

Adoptive and foster homes for children offer the same type of home environment as would the natural home. Whereas we consider adoptive homes as being synonymous with the natural home, we view foster homes as providing opportunities for foster parents to get acquainted with mentally retarded children before eventually adopting them. All of the support services available in Priority I are also available to adoptive and foster parents.

Priority III - Community Living Arrangements

residential
continuum

In April 1972, the Pennsylvania Department of Public Welfare (DPW) initiated the Community Living Arrangements Program (CLA). Though the CLA continuum of residential services was based on the residential continuum developed in Omaha, Nebraska, in the late 1960's, it was somewhat revised to be more Pennsylvania specific.

In contrast to the 1.7 million dollar budget for the first year of the CLA Program, the budget for the present fiscal year is 16.1 million dollars. This program currently has over 2,200 people in residence and has served another 1,200 individuals who have left the program to live independently in the community or to move back home with their families.

state
dollars

The Pennsylvania CLA Program is 100% state deficit funded with the basic funding being state dollars. Though far less than the state monies earmarked for the CLA Program, a source of outside income is residents' room and board payments derived primarily from their Supplemental Security Income (SSI) benefits or from any other source of income. Providers currently charge residents an average of $130 a month for room and board. Of course, those residents who lease their own apartments directly from a landlord may pay more than this amount.

The CLA Program is progam funded; that is, each agency providing residential services receives an annual cash grant on a quarterly basis from the counties. The provider agencies receive the first quarter at the beginning of the fiscal year; however, from the second quarter they bill the county monthly for approved line-item expenditures.

private providers

Initital funding is predicated on the submission of a residential services plan by the county. After approval and funding of the plan, the county may decide to provide residential services itself or contract with a private provider. With a few exceptions, counties in Pennsylvania elect to contract with private providers, most of which are non-profit. We do allow counties to contract with profit-making providers. At present we have two such providers in Pennsylvania.

assessment

After the counties receive notification of available funding, they may request private provider agencies to submit applications indicating their willingness and ability to provide the necessary residential services. Actually, a questionnaire based on the sophisticated instrument, **Program Analysis of Service Systems (PASS)** is used to evaluate CLA programs. The approved application is all that is necessary for a private provider agency to receive funding. It need not have private funds, staff or a facility.

Also tied into the residential funding, beginning July 1, 1976, is the automatic funding of 90% of the cost of vocational (workshop) training for residents entering newly funded CLA programs. The county is responsible for the remaining 10% of the cost for this training.

vocational training

The following three major criteria must be met to receive these vocational training monies:

- All residents must attend day programs outside their living accommodations;
- To the greatest possible degree, natural parents and/or the family should be kept involved in the vocational development of the CLA resident; and
- Because of our concern with deinstitutionalization and prevention of institutionalization, we ask that 50% of the CLA residents be from public or private institutions and 50% from the community.

The CLA Program was developed to provide a continuum of community-based residential services as alternatives to institutionalization. This continuum for residents of all ages and functional levels is as follows:

- Developmental Maximation Unit:

  Medically complex or multi-handicapped individuals live in this type of CLA Program because they need special medical care along with basic developmental training.

- Intensive Habit Shaping:

  To acquire adequate personal-care habits and to change severe behavioral problems, severely and profoundly retarded persons live in this type of program but only on a temporary basis -- approximately 12 to 18 months.

- Structured Correctional:

  Difficult-to-manage retarded persons, especially those with anti-social behavior, participate in this type of program.

- Child Development:

  The primary goal of community placement for retarded individuals ranging in age from birth to approximately 18 is to provide both developmental training and also the teaching of skills normally learned at home.

- Adult Training:

  Retarded adults -- aged 18 and over -- participate in this CLA program to develop and, if possible, to master the social skills necessary for integration into the mainstream of the community.

- Adult Minimal Supervision:

  After having developed and mastered the skills necessary for integration into the community, this type of CLA program enables retarded adults to have minimal staff assistance before moving into completely independent living situations.

- Family Relief:

  This kind of CLA program offers an alternative to institutionalization for persons who require short-term emergency or relief care for their retarded family member(s).

priorities

Regarding the community residential situation most conducive to a person's development toward his or her greatest potential, we consider - as emphasized earlier - the natural home for children and independent living accommodations for adults as being our first priority. Nevertheless, since many individuals with special needs have not been able to have these needs met through living either in their natural homes (if children) or in independent living situations (if adults) we developed supervised residential alternatives.

In our early years most of these settings were group homes for six to eight residents and an appropriate number of live-in staff. Eventually, however, many group home providers recognized the need to expand from group homes to smaller and less restrictive residential settings. While providers of adult group homes were largely responsible for initiating this movement, providers of children's programs soon followed, with Mercer County ARC implementing the first children's apartment program in Pennsylvania.

children's apartment

This trend has caused a dramatic change in the overall appearance of the CLA Program. For instance, in the first two years of operation we funded 100 group homes and only 50 apartments; whereas, in the past two and one-half years we have implemented over 400 apartment and small home programs and only 25 group homes.

Since our providers have demonstrated that they can provide better services in smaller, less restrictive environments than are found in group homes, we prefer to fund few new group home programs. As regards existing group homes, we have no policy to phase them out. The future of group homes, however, would seem to fall within the following parameters:

group homes

- To provide residential services as originally approved and funded;
- To provide residential services of a more specialized nature;
- To serve as core residential programs to less restrictive satellite residential programs;
- To be sold or leased to other agencies providing services for non-retarded individuals who have special residential needs.

Priority IV - Nursing Homes

This type of living situation is for the aged mentally retarded individual who has no other more appropriate (or available) residential alternative.

nursing homes

Priority V - Institution

When the social services system doesn't offer the preceding four priorities, the public or private institution would be a residential alternative.

institutions

The following section discusses the Pennsylvania Base Service Unit function, Mental Retardation Unit function and the procedure to place individuals in CLA programs:

At a minimum, the Base Service Unit, a component of the County Mental Health/Mental Retardation System, performs the following functions:

base service unit

- Intake study;
- Referral;
- Development of an individual comprehensive program;
- Coordination of client services; and
- Monitoring of client service.

The Base Service Unit may deliver the service either directly or through arrangement with other resources; however, the Base Service Unit maintains responsibility for ensuring continuity of program for each client by coordinating resources toward that end.

procedures for placemen

The Mental Retardation Unit, a component of the Base Service Unit, provides the above services to individuals with mental retardation. This specialized unit has expertise in the provision and delivery of these services and develops long and short-range goals and program plans for every life sphere.

Procedures for placement of an individual in the CLA Program include:

- Referral of the potential client to Base Service Unit/Mental Retardation Unit;
- Base Service Unit/Mental Retardation Unit intake and client interview;
- Transfer of current evaluations and records;
- Base Service Unit/Mental Retardation staff meet to develop individualized program plan;
- Referral to the CLA Program;
- Meeting of Base Service Unit/Mental Retardation Unit staff, project director and potential resident managers;
- Interview with client and all involved persons;
- Client's trial visit for a minimum of one evening and one weekend;
- Communication to set up day program for the client;
- Meeting with Community Living Arrangements staff and Base Service Unit/Mental Retardation Unit staff regarding final decision;

- Placement if appropriate; and
- Follow up and involvement of agency, institution and/or family in the client's program plan.

Many of the above activities take place in a simultaneous, rather than in sequential, order. This allows the greatest degree of cooperative planning.

The client and/or his legally appointed guardian are involved in each aspect of this process. Decision making by the client takes place at each step.

Before ending this overview of the CLA Program, a key issue - accountability - merits emphasis. Because the CLA Program of Pennsylvania each year has its own identity in a specific legislative appropriation, it is critical that we demonstrate the highest amount of quality at the lowest possible cost. To accomplish this end we have developed the following three accountability mechanisms:

accountability

- Individual Assessment through the Use of **Assessing Basic Competence**, an instrument specifically developed for the CLA Program;
- Program Assessment through the use of **Program Analysis of Service Systems (PASS)**; and
- Fiscal Accountability through the annual use of a fiscal audit format that staff of the Pennsylvania Auditor General's Office designed specifically for the CLA Program.

As regards the future of the CLA Program and the role that the Pennsylvania Association for Retarded Citizens (PARC) will play in that future, we envision that PARC -- so instrumental in the initial development of the CLA Program -- will have the even more important role of monitoring and insuring that the "system" being used enhances the quality of life for mentally retarded citizens of Pennsylvania.

A Community System

Eastern Nebraska Community Office of Retardation

BARRY LAMONT

This presentation will give an overview of the Eastern Nebraska Community Office of Retardation (ENCOR) service system. Brief overviews will be given pertaining to eligibility criteria for service and program components within ENCOR. The main emphasis will be on the management model for the ENCOR Residential Division. How and what type of residential services are provided, funding sources and issues surrounding them will be discussed in relation to residential services. In addition, a brief description of regulations, standards, codes, laws, etc. that affect the operations of ENCOR's Residential Services will be presented.

ELIGIBILITY FOR SERVICES

ENCOR is designed to provide services to mentally retarded individuals in a five-county geographic area of Eastern Nebraska. The criteria for services is met by a diagnosis of mental retardation as the primary disability. In addition to the major disability being mental retardation, the individual must be a resident of the five-county area in which ENCOR provides services. However, inter-institutional transfers from other states, when families move to the five-county ENCOR area, will also be considered for services. Only when all service needs are met from the five-county area would services be considered for persons outside the catchment area for ENCOR.

The process of obtaining services for individuals has been through inquiries to the agency's Guidance Division. Once inquiry has been made an advisor is assigned to assist in completing application forms and collecting the proper information to determine eligibility. Again, the main question for eligibility is mental retardation which can be determined through review of current psychological examinations. In addition, residency within the five-county area is also considered. If there are no current psychological evaluations, appointments will be made with generic services within the community to provide an assessment for the prospective client.

profile information

The inquiry should provide a basic profile of the person who is seeking services from ENCOR. Further profile information will be collected through the use of other professional evaluations such as medical, behavioral, speech and additional specific areas according to the person's basic needs. Not all prospective clients applying for services will be evaluated by speech, occupational or physical therapists. Only those clients who, through physical and psychological examinations, have been identified as potentially needing service in specialized areas such as speech, physical therapy, etc. will be evaluated by those professionals. The inquiry also determines from guardians, parents and the mentally retarded individual what they consider to be their service needs.

Once this profile has been completed and a needs assessment of the individual outlined, the advisor and additional professionals from specific service areas will determine if there are services available within the community outside the ENCOR system. It has been a main goal, since ENCOR's development in 1969, not to duplicate services. If services are available through generic agencies within the community, those services should be sought out and used rather than developing and duplicating such services. In some instances, this may require that professionals in the field of mental retardation assist generic agencies in developing service continuums which adequately provide for the mentally retarded persons in the community as well as other service populations.

generic services

If it is determined that there are no other services available within the community that meet the needs of the client, ENCOR services will then be provided. All these services, most prominently Residential Services, will be provided in a least restrictive fashion. It is ENCOR's intent to support, not supplant, the natural home. The best atmosphere for a mentally retarded person, or any person, is his natural home. If services can be provided to the family which allow that family to maintain their son or daughter at home, this service is much more appropriate than removal of a person from his/her natural home in order to provide services.

natural home

In considering least restrictive services it is important to provide only what is necessary. For example, an individual could live in the community on his own except that he is unable to balance a checkbook properly or grocery shop independently. It would be overkill to provide 24-hour residential services to this person. Why not arrange for an advocate or staff member to stop by once or twice a week to assist the person in balancing a checkbook and in menu preparation and grocery shopping. The goal is to provide only what is necessary for the person to live in the community. ENCOR is attempting this type of service delivery through its alternative living unit (ALU) program.

alternative
living
units

An ALU is anything the mentally retarded person needs, not just what the agency has available. It is a tailor-made living situation. This living situation is designed by the mentally retarded person, his family, ENCOR Residential staff and other professionals such as psychologist, physician, nurse, teacher, etc.

PROGRAM COMPONENTS

In addition to the Residential Division within ENCOR there are four other divisions or departments. Those departments are Vocational, Educational, Guidance and Administration. The Residential Division will be described fully in the remainder of this presentation. The four other departments will be briefly discussed at this time.

ENCOR is part of an umbrella agency system called ENHSA (Eastern Nebraska Human Services Agency). Through this umbrella agency, ENCOR receives its administrative services. These services include Personnel, Payroll, Bookkeeping, Maintenance and Transportation Services. ENCOR contracts for these services from ENHSA and annually pays the umbrella agency a percentage of its revenues. This percentage is based on the percent of use by ENCOR of each service provided by the umbrella agency.

umbrella
agency

The Vocational Division within ENCOR provides a continuum of vocational services, starting with the Industrial Training Center (ITC). The ITC provides basic skill training in six broad areas: work skills, socialization, academics, self-management, communication and community access. The next step in the continuum is Northeast Industries, which provides advanced industrial training in a machine-intensive, production-oriented environment. This intermediate step provides for more complex skills training before individuals move to skilled employment. From the advanced workshop the continuum flows into Work Stations in Industry. The agency contracts with an existing industry to provide specific services on the floor of the industry. From Work Stations in Industry the continuum goes to placement into competitive employment. Staff are assigned to assist mentally retarded individuals who are eligible for competitive employment. Placement staff assist persons in finding a job and provide follow-up services to these persons to assure that their transition to competitive employment will be successful.

industrial
training
center

educational

The Educational Department provides two basic types of services. Since there is mandatory education presently enacted in Nebraska, the Public School Systems are required to provide educational services to all individuals regardless of their handicap. ENCOR's Educational Department is concerned with educational intervention for preschool mentally retarded children. One program is the integrated preschool program where the Educational Department of ENCOR contracts with existing preschools within the community to provide services to mentally retarded children. The agency, in turn, provides additional staff and funds to assist the preschool in providing an integrated program. The other program provided by the Educational Department is a program called CEEP (Coordinated Early Education Program). The CEEP Program provides home trainers to visit families in the community who have mentally retarded children still in the home. These home trainers provide families with teaching methods and programs to assist in helping their mentally retarded son or daughter to develop.

guidance

The Guidance Division provides an advisor to each mentally retarded individual who is receiving services from ENCOR (many individuals receive only guidance service from the agency). The advisor is a liaison for the mentally retarded person between ENCOR and any generic service agencies within the community that an ENCOR client may be seeking services from. One of the main functions of the department is for advisors to act as the chairperson or leader for an individual's IPP (Individual Program Plan). This planning process occurs formally once every six months and is reviewed every three months, or more often if necessary.

INDIVIDUAL PROGRAM PLAN

individual
program plan

The individual program plan (IPP) is the tool used by the agency to design a program to meet the needs of each individual served. This is the most important process that takes place for a client. It is designed to determine exactly what an individual's needs are in all areas (residential, vocational, educational, etc.) and to establish goals accordingly. This process also monitors an individual's progress and, from that progress, determines further goals or options available for the client.

IPP team

Naturally, the client is the first person involved in this planning process. To ensure that all planning and service delivery within the system of ENCOR follow the principle of normalization, mentally retarded individuals receiving services are the primary concern in any process. In addition to the mentally retarded individual himself, any family members, guardians or advocates can be participants on the IPP team along with agency para-professional and professional staff and other community professionals involved in the person's program. Agency para-professionals and professionals would include residential staff who work with the individual on a day-to-day basis as well as vocational staff or educational staff and the individual's advisor, who acts as the chairperson for the IPP team. Outside professionals may include nurses, physicians, psychologists, psychiatrists, etc.

goals

As mentioned earlier, the IPP process is used to develop goals and review progress for an individual. Objectives must be measurable and a means for measurement established. Many means of measurement can be used to determine growth toward objectives, including precision teaching, daily logs and activity sheets.

least restrictive

Data may indicate that an individual is ready for a less restrictive residential setting. This might involve the individual moving to a smaller residential setting where he could afford to live by himself or with one or two other roommates. It might also mean that residential staff presently living with the individual move out and/or provide fewer staff hours to the client. The reverse could occur if an IPP review showed that the individual was having trouble reaching specific goals and that a more structured setting was required. In this situation, the client might move to a more structured living arrangement or additional staff hours could be provided in the present residential setting.

In determining staff required for a residential setting, it is the client's needs that are considered. Any pattern of staffing that best serves the client's needs is planned for. This could result in a part-time staff for one, two or three clients or one, two or three staff for one client. The type of staff for an ALU is again dependent on the client's needs.

RESIDENTIAL SERVICES

core residence

The ENCOR Residential Division provides services through a continuum of residential programs. The Division is set up on a geographical basis; i.e., the five counties are divided into specific geographical areas. Within these areas one individual, a Residential Coordinator, is in charge of all residential settings for both children and adults. The residential settings are divided into clusters. A residential cluster centers around a core residence. This residence serves as an evaluation center and highly structured living environment in addition to being the administrative hub, or mother house, to satellite residential settings called Alternative Living Units (ALUs).

ALUs are smaller, individualized, residential locations housing no more than three mentally retarded individuals. These settings take the form of apartments, rented houses, duplexes, etc. They are most often rented by the mentally retarded individuals themselves or in conjunction with

Residential staff members who live with the clients. Each of the ALUs is a small residential setting which has been specifically designed and staffed to serve the individuals there.

Since attempts are made to tailor residential settings to specific individuals' needs, none of the 95 residential locations ENCOR provides are exactly alike. The differences are due to the specific service systems each location has developed to meet the needs of the mentally retarded persons living in these residences.

residential manager

The residential cluster is managed by a Residential Manager, with assistance from two to three assistants. Assistant Managers have specific responsibilities for management and monitoring of either the core residence or the administratively attached ALUs. The number of ALUs attached to any one core residence determines the number of Assistant Managers operating within that residential cluster.

area coordinator

The residential cluster makes up part of a residential area. In all residential areas there are at least three, and as many as six, residential clusters. These clusters are supervised by an Area Coordinator. The Area Coordinator acts as a monitor for his area as well as a resource person for the residential staff. The Residential Coordinators are responsible to the Director of the Residential Division.

division director

The Division Director acts somewhat the same as the Residential Coordinators do in monitoring all of the residential areas and serves as a resource to the Area Coordinators, in addition to maintaining administrative data and providing management necessary to maintain the Division.

MONITORING

The most important part of ENCOR's Residential Division is the monitoring function. Monitoring is done in a variety of ways. The most basic and common monitoring activity in the system involves visits by residential staff to residential settings.

weekly visits

On a residential cluster basis, visits are provided or completed by Assistant Managers and the residential cluster manager. Visits occur no less than one per week to every residential facility within that cluster. These visits include a review of all administrative paperwork plus a survey of the living conditions within that residence. The monitoring supervisor also provides any resources necessary at this time and assists the residential staff in problem solving or in acquiring the appropriate professionals to assist in problem areas. In addition to on-site visits, the residential staff have a cluster meeting each week to disseminate information within the system. The cluster meetings and site visits are documented in "contact reports" and minutes which are provided to the Area Coordinator.

The Area Coordinator, in turn, provides exactly the same type of monitoring, visiting every residential location within his or her area at least once every three months. The Coordinator must visit all core residences in his area weekly, writing contact reports on each visit. These are then provided to the facility visited and the Residential Division Director. In addition, weekly area meetings are held by the Area Coordinator with his management staff to disseminate any information upward or downward through the system and to provide a forum for decision making and problem solving on an area level.

The Residential Division Director holds weekly meetings with the Residential Coordinators to disseminate information within the system as well as to develop division policies, procedures, etc. The Director also makes unannounced visits to any residential facilities within the system like the Residential Manager or Coordinator. He monitors and acts as a resource for the residence staff and clients.

FUNDING

The ENCOR Residential Division receives funding from four basic sources: federal funds, state general funds, county and municipal government funds and fee schedule payments from primary and secondary consumers. These four basic areas will be briefly described.

federal funds

The federal funding sources include Title XX, federal grants and SSI monies. In addition to these funding sources, the agency is presently involved in determining eligibility and acquiring Title XIX funds. The major funding source for the agency and the Residential Division is Title XX payments.

state funds

State general funds are provided through the state's Office of Mental Retardation which acts as a monitoring, consulting and funding body at the state level for all regional community-based programs. Annual budgets are submitted to the Office of Mental Retardation where funding allocations are determined for ENCOR as well as the five other community service regions within the state. State general funds, through the Office of Mental Retardation, are the second largest funding source for ENCOR.

county funds

The county funds provided to ENCOR are paid from each participating county and are determined by the separate County Commissions. An inter-local agreement was originally written which stipulated funding maximums and minimums for the participating counties. These county funds are used mainly as matching funds for state and federal monies.

fee schedules

Fee schedule payments by primary and secondary consumers are the fourth major funding source within ENCOR. Fee schedules are determined by the state through the Office of Mental Retardation and apply to secondary consumers or parents. Primary fee schedules involve room and board payments by mentally retarded adults. At present, these payments are $175 per month.

In total, these funding sources provide a fiscal budget (1976-1977) for the ENCOR Residential Division of approximately 2.2 million dollars to provide services to 200 existing residential clients and a planned 30 new clients. The agency, on a whole, provides services to 1,000 mentally retarded individuals within the five-county area.

FUNDING ISSUES

Stability and durability of funding is always a concern in social service systems. This concern usually results from the requirement to fund long-term programs with short-term monies. In budgeting for residential services on short-term money there is always the question: "Will we be able to provide these residential services to clients next year if our present funding sources modify or change?"

increased costs

Stability in the amount of funds provided for residential services is a concern, since service systems grow and as the system grows the amount of funds required to implement new services and maintain administrative structures increases dramatically. In addition to the regular growth rate causing increased costs in residential systems, there is the inflation rate, which directly affects the cost of housing, food, utilities, etc.

funding criteria

There are also problems in funding sources which are earmarked for specific types of residential services. These specific services often do not meet the needs of the clients within the system. This often results in specialized services being developed or provided to individuals which do not fit the funding body's criteria for use of funds. This, in turn, results in lengthy negotiations with funding sources and apply for exceptions in funding criteria to provide services in a fashion other than their recognized uses.

Many times stringent earmarking by funding agencies creates a situation in which the nature of the services provided is determined by the funding sources as opposed to the needs of the clients.

Through ENCOR's experience of developing different residential service systems and continuums it has become apparent that funding sources must be channeled for use in a wide variety of innovative residential services rather than specific service types. An example of the limitations these funding sources are creating in the provision of residential services is the very small percentage of funds available to provide services of a residential nature in a person's natural home. The ultimate goal of ENCOR is for all mentally retarded individuals to live in the least restrictive residential setting possible or, in the case of children, to be able to return to or remain in their natural home. Funding sources, as they now exist, allow for very few services to be provided in the natural home. In-home services would prevent the mentally retarded person from having to leave the home to receive appropriate services. If sources were properly oriented funds could be used in a preventive fashion rather than in specific residential service types requiring a person to move from his home.

limitations

REGULATIONS, STANDARDS AND CODES

There are a multitude of standards and codes and, of course, evaluative bodies to measure the compliance with standards in residential systems throughout the country. ENCOR is by no means exempt from these evaluations. Annually the ENCOR Residential Division can count on a minimum of six major program evaluations to determine anything from funding eligibility, licensing capability and/or renewal of licenses to accreditation. These regulations and standards are derived and implemented from three basic governmental levels: federal, state and local. There are also independent monitoring bodies in existence which the ENCOR agency and Residential Division participate in such as AC/MR-DD (Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons.)

evaluations

The federal level involves monitoring to assure compliance with regulations of funding sources. Compliance with such standards and regulations allows for continued funding from such sources as Title XX and Title XIX. The regulations cover a wide variety of areas including administrative, programmatic, environmental, health, medical and safety issues. These evaluations are usually required on an annual basis.

compliance

At the state level ENCOR must maintain compliance with life safety codes maintained by state and local fire marshals, Office of Mental Retardation standards and regulations and Developmental Disability Center licensing regulations. These regulations are similar to those mentioned above, covering a wide variety of areas.

Local regulations involve such things as zoning ordinances which require us to seek zoning exceptions or rezoning petitions in order to implement programs in specific areas.

cooperative assessments

The impact of these many different evaluating groups and sets of standards, regulations and codes is quite devastating to the Residential Division of ENCOR. This is due to the voluminous amount of time required by staff to prepare for evaluation visits. The data collection and organization to meet an evaluating group's format often takes many more hours of staff time than the actual on-site evaluation. In the long run, this is detrimental to service provision due to the long hours direct service staff must put into preparing for the evaluating groups instead of providing direct care to residential clients. Although evaluations and monitoring of the ENCOR Residential System are welcomed and encouraged, it is often felt that a cooperative evaluation by several evaluating groups at the same time would be as productive in assisting the agency to develop and improve service delivery. This format would be less time consuming and more efficient for the operation of the Residential System.

In summary, the ENCOR Residential Division is a highly complex service delivery system providing a wide variety of residential continuua. The system does work although it is not perfect, and problems do occur as in all social service systems.

future goals

The most important thing to be done by ENCOR in the near future will be to develop services to support families and allow them to maintain their mentally retarded son or daughter in their home and avoid the use of residential services requiring the mentally retarded family member to leave his or her natural home. Until these types of services are developed, ENCOR and other service delivery systems throughout the country will always be playing a catch-up game in providing services. If proper preventive services are initiated, the ugly and presently unpreventable waiting list for residential services may eventually be eliminated.

Foster Families

Macomb - Oakland Regional Center

GERALD PROVENCAL

The recent history of deinstitutionalization shows a clear preference for four types of community residential settings. Rosen and Callan reported in 1972 that the highest percentage of community placements were made into the homes of the client's parent or guardian. Nursing homes, group homes and foster homes, respectively, were the next most frequently selected institutional alternatives.[1] Two years later Scheerenberger found that these same four residential options continued to receive nearly 80 percent of all institutional graduates.[2] A significant difference, however, was in the area of group home growth. The percentage of people entering group homes from institutions increased by 124 percent between 1972 and 1974. Group homes represented the institutional alternative most often turned to, other than the client's own home.

While the number of institutional people finding new homes in the larger community has been increasing, foster homes still remain the least used of the major residential possibilities. To put it another way, of the "big four," foster homes are solidly in last place.

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[1] Rosen, D. & Callan, B. Trends in Residential Services for the Mentally Retarded. Madison, Wisconsin: National Association of Superintendents of Public Residential Facilities, 1972.

[2] Scheerenberger, R. C. Current Trends and Status of Public Residential Services for the Mentally Retarded. Madison, Wisconsin: National Association of Superintendents of Public Residential Facilities, 1974.

normalization

That foster homes should occupy such a lowly position is somewhat puzzling. Professionals within the field popularly espouse the normalization principle, and deinstitutionalization is frequently championed as evidence of this tenet in practice.

In keeping with normalization, it would seem that the qualities inherent in a small foster home would be strongly championed by professionals. Certainly, for children, any comparison between foster home and group home characteristics must find the former in closer proximity than the latter to the Wolfensberger definition of normalization. . .

> "Utilization of means which are culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are culturally normative as possible."[3]

weaknesses

Rather than promoting foster home strengths, however, professionals frequently turn attention toward its limitations. The following are four commonly attributed weaknesses of foster homes.

- Foster parents can only cope with easy clients.
- Foster parents might give love and good physical care, but they can't give program.
- Foster homes are too difficult to monitor.
- It's impossible to find good foster parents.

confidence

This limited acceptance does not appear to be confined to professionals. When suggesting to natural parents that their son or daughter might be well suited for a foster home, it is not unusual to experience stronger opposition to this than to any other type of placement. The following reason, given by a parent recently for her lack of confidence in foster care, is representative. "If he can't be cared for in his own home--and we have tried everything--how can he be cared for in someone else's home?"

In the summer of 1973 the Macomb-Oakland Regional Center began a deinstitutionalization project. Basically, the objectives were to move as many institutional residents as could benefit to the larger community and to provide community-based residential options for individuals seeking traditional admission.

It was clear from the beginning that if the objectives were to be met maximal utility of existing resources was a necessity. It was just as clear that new models of residential service and new approaches to old models would be needed if the project were to be successful. Agency studies were subsequently undertaken to determine how to improve upon the availability, versatility and quality of all operating community residential models.

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[3] Wolfensberger, W. The Principle of Normalization in Human Services. Toronto, Canada: National Institute on Mental Retardation, 1972.

This paper focuses on an innovative variation of the foster home concept. Specifically, it describes the Community Training Home. The features which make this model different from the traditional foster home and provide the basis for its increased potential as an institutional alternative are discussed in detail.

community training home

The Community Training Home is a community-based residence built upon the foster home model. Approved foster parents, or parent, provide room, board, supervision and in-house programming for one to three residents. Additional, and separate, funding is available for the in-house programming which is contracted for by the service agency. The latter provides case manager and consultative services and requires foster parents' participation in a skill training program. Written monthly reports by foster parents provide valuable monitoring tools.

IN-HOUSE PROGRAMMING

One of the constant companions of foster parents has always been meager payment for services. The common inadequacy of remuneration was put this way by a New Jersey woman. "The money the state pays is barely enough to manage and does not compensate for the time and attention (which) should be given to the three new members of (my) family. I do it because I like it, and I'll keep doing it until I can't. But don't get in it unless your heart is in it."[4]

The recognition that payment for services was inadequate, when combined with the criticisms leveled by professionals that foster parents lack training and primarily offer only tender loving care, helped bring about a partial solution to both problems.

A separate distinction was made between room, board and supervision and a new category of foster parent services called "in-house programming." The expectations of the former three services remained as they always had been: essentially to provide housing, meals and guidance to a resident.

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[4] Witlow, J. Families help retarded escape institutional life. Star-Ledger. Newark, New Jersey, February 23, 1975.

In-house programming, on the other hand, encompassed an entirely new set of expectations. This service can best be described as "training within the home given by the foster parent to the client resident." The focus of training is determined by the individual needs of the resident and must be complementary to other active programs. Specific behavioral objectives, linked to habilitative goals, are selected by an interdisciplinary team for each resident, and these objectives are determined only after reviewing all of the client's needs.

team support

In addition to the designation of certain training objectives, behaviorally specific methodologies leading to each particular objective are provided to the foster parent. These methodologies are individualized and are written in non-technical language.

It is essential to emphasize the fact that all persons in community placement are actively involved in daily activities outside the home; i.e., school, work, sheltered employment, prevocational training. These day activities are seen as carrying the primary responsibilities for formal program, with the in-house programming concept viewed as a complementary supplement. As a result, assuring a positive interrelationship between the client's life within his or her home and community is an extremely important part of the case manager's responsibility.

activities

Funding

Separate funding sources and mechanisms were arranged for, in keeping with the distinct categories of foster parent service. The result was that payment could be made at the usual rate for room, board and supervision, with an additional amount made available for in-house programming.

While budgets vary, a simple description of payment to the foster parent follows:

> Room, board and supervision costs are covered for all Macomb-Oakland Regional Center clients by Supplemental Security Income (SSI) grants. There are two possible levels of SSI payments, depending upon a particular client's level of need: $7.62 per day for a client requiring **domicillary care** and $9.95 per day for a more involved individual requiring **personal care**.* (Virtually all clients receiving in-house programs require the personal care level of service.) In order to receive the care amount specified the foster parent must satisfy the room, board and supervision expectations stated previously.

budgets

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*These figures represent typical costs as of July 1976.

In-house program contracts are written for amounts in addition to that paid for the provisions of **domicillary or personal care.**

A typical in-house program contract will call for the foster parent to spend two hours per day working on four predetermined individual client objectives. Payment for the two hours spent in program is made at a standard $2.50 per hour rate or $5.00 for the day. This daily $5.00, added to the typical $9.95 for room, board and supervision for an individual with a personal care level of need totals $14.95 per day, or approximately $105.00 per week.

program
contracts

Contract Agreement

In order to assure clear understanding of responsibilities, a contractual agreement is drawn up between the agency and the foster parents (See Appendix I). The contract includes all areas of service to be rendered the client and purchased by the agency. Specific habilitative objectives are a part of the program contract as well as the daily amount of time expected to be spent on each. Of course, the responsibilities inherent to room, board and supervision are also part of the agreement. Exact dollar amounts to be paid the foster parents, as well as community programs the client will participate within, are part of the contract. While individual objectives are reviewed no less than monthly, the total program contract is renewable on a yearly basis. Contracts may be dissolved by either party at any time.

monthly
reports

EXPANDING FOSTER PARENT SKILLS

In an attempt to extend the foster parent's ability beyond the focus of "tender loving care," formal education and training programs were established.

The degree of emphasis given to preparing foster parents for their job in the Macomb-Oakland Regional Center model appears to differ significantly from many deinstitutionalization efforts. The American Association on Mental Deficiency's Mental Retardation publication helps in recognizing this difference. A review of the periodical, over the past five years, reflects a better than twenty-to-one interest in preparing the client to move to the community in contrast to preparing any of those people (natural, foster, group home parents) to receive the client. While I am not suggesting the curtailment of client readiness programming, there obviously needs to be much more attention placed upon readying natural or surrogate parents to live and work with the individual who is reentering the greater community.

Experience at the Macomb-Oakland Regional Center has led to the belief that the likelihood of a client making a successful adjustment in community placement is dependent more upon the degree to which the parent is prepared than the client is readied. There have not emerged, for example, any absolutely essential client skills, intellectual levels or behavioral controls which are prerequisites to successful community adjustment. What has emerged as essential is simply that the parent, whether natural or surrogate, must be prepared emotionally, intellectually and behaviorally to accept the client where the client is.

continuing
education

The education/training requirements for foster parents operating community training homes call for their participation in inservice and continuing education programs. The former encompass from five to eight sessions of approximately three hours each. The topics covered include:

- An Orientation to Mental Retardation
- Normalization
- Maintaining Safe Environments
- Fire and Safety Considerations
- Changing Behavior
- Administrative Considerations
- Leisure Time Activities
- Community Placement

monthly
meetings

In addition to the inservice component, participation in monthly meetings for the purpose of continuing education and increasing skills acquisition are foster parent requirements.

Treatment of subject areas within either inservice or continuing education remains consistently serious and ambitious in scope. Learning objectives, discussion stimulants, demonstrations, role-playing, simulated exercises are all given active parts within each session.

The linkage between foster parent training and in-house programming for clients is obviously a critical one. The individual objectives which make up the heart of the program contract can only be pursued by people who have a foundation of skill training. It is difficult to imagine one being present without the other. Clearly, the intent and emphasis of this education/training and in-house programming is to radically alter the previously stated preconception of "Foster parents (who) might give love and physical care but (they) can't give program."

MONITORING

The demand for accountability is frequently heard in mental retardation services today. If there was ever a mood that allowed programs to be financed primarily because there was an obvious need, that mood has changed. There are very real and pervasive pressures being placed upon agencies to become more conscious of where their budgeted dollar is going. While the presence of such auditing/management type constraints is sometimes viewed as an undesirable intrusion on the domain of human service delivery, it can be useful.

accountability

Historically it has been difficult to monitor foster homes. That difficulty was not because satisfactory provision of room, board or supervision was too elusive to determine; rather, it has been problematic because inadequate funding of foster homes made it hard for the case manager to be critical about what he or she saw. As a social worker pointed out a few years ago: "It is very hard to correct a foster parent for 'spoiling' a resident when she gets about the same amount of money to care for that boy as it costs to board your dog."

The added funding and formal contractual agreement between foster parent and service agency has given the case manager a more defensible vantage point from which to monitor foster parent influence on the client. This includes the effect of subtle nuances as well as more open action and reaction patterns.

guidance

In addition to the in-house program contract, which introduces a positive monitoring advantage to the role of the case manager, there are distinct advantages to the foster parent as well. The foster parent has an opportunity to increase skills through formal training, receive fair remuneration for fair labor and presumably watch the client develop at greater pace than if there were no specific program in the home.

Monthly Reports

In order to keep the case manager current on progress being made toward in-house program objectives, monthly reports are completed by foster parents. These reports (See Appendix II) are either given or mailed to the case manager on a monthly basis. While there is more information contained within the report than just the status of in-house objectives, this does provide a focal point for review and discussion.

reporting

The monthly report provides a veritable chronical of the client's activity over the previous four weeks. Degree of movement toward objectives, unusual problems, social-recreational participation and medication changes are just a few of the areas consistently reviewed between the case manager and foster parent with the assistance of these reports.

Rather than perceiving monthly reporting as useless paperwork, foster parents can take this opportunity to give themselves credit for all the effort they have in fact put in with the resident. This scheduled requirement of recording client progress, activity and overall status is typically seen by the foster parent as a direct reflection of their commitment to the client.

case manager

The combination of separate payment for in-house programming, monthly reporting of effort spent on the behalf of the resident and frequent visitation (an average of 2.5 visits per month) with the case manager has upgraded the service rendered the client as well as the relationship between agency and provider. The martyrdom so common to traditional foster parents has been replaced by a more equitable sharing of responsibility and reward.

There are additional advantages to combining the distinct features of this model. Both case manager and foster parents alike appear to raise the expectations they hold for one another's behavior. The contract, bolstered by the frequency of written reporting and meetings for progress review, requires more from each than previously was the case.

Periodic Reviews

While individual client objectives can be altered whenever the case manager, consultant and foster parents agree it advisable, they are discussed monthly and all habilitative planning is thoroughly evaluated on a yearly basis.

FINDING FOSTER PARENTS

The reservations about foster care which were stated earlier, and attributed to professionals and parents, indicated that this institutional alternative suffered from an image problem. In order to maximize its potential it became clear that foster parents' roles needed a rather dramatic upgrading. With the addition of the in-house programming concept, accompanied by payment and skill training, the position of the foster parent has taken on an increased respectability. A direct benefit of improving the image and rewards of foster parenting is that possibilities for recruitment took on a new optimistic dimension. Increased payment, in particular, opened the doors to individuals who have long had the skills and perhaps even the desire but not the income that would allow their staying home and making a major habilitation commitment to a retarded person.

fees

Under the present system potential foster parents can look forward to making a financial contribution to their household (average weekly amount for one client = $105; two clients = $210; three clients = $315) as well as making a positive impact on the life or lives of retarded persons.

Let there be no mistaken notion that being a foster parent is an "easy" way to make money. To be sure, the demands on the foster parent participating in this program are tremendous. The requirements as previously detailed are far greater, for example, than those placed on the more familiar "room, board and supervision programs." In the community training home model foster parents are regarded as paraprofessionals. Frequently they become so skilled and knowledgeable about clients that case managers respond to them as co-equal colleagues.

Home Development Staff

Efforts to recruit foster parents often seem to be fragmented within agencies. Social workers, intake workers and others with major ongoing responsibilities are also given the task of screening foster home applicants. In only the most atypical agencies are there any staff with sole responsibilities for actually promoting the growth of new homes.

The Macomb-Oakland Regional Center program has had consistently good recruitment results which can, in significant measure, be attributed to the creation of a specialty "development staff." Over the past three and one-half years there has been an average of slightly less than two persons working on the single task of finding new community training homes. Because their roles and time have been protected from secondary assignments development staff have been able to perfect a variety of techniques which have resulted in over 175 community training homes.

staff
support

Recruitment Approaches

While the development staff have employed a variety of novel approaches to stimulate interest in foster parenting, a single theme has been maintained throughout. All promotional efforts highlight the advantages of the job and not the plight of the retarded. There is a substantial difference between the two. Whatever the particular medium used, emphasis is consistently directed toward the challenges and rewards of foster care in the Macomb-Oakland Regional Center program. Mentally retarded persons are never, under any circumstances, made to appear in desperate need of charity or personal sacrifice. This fact assures both the maintenance of respect and dignity for clients as it establishes a context for the future relationship with the foster parents.

recruitment

Classified Advertisements

Of the several productive methods utilized to reach potential recruits, none has proven so consistently effective as the classified ad. Before actually placing the first advertisement in a local daily newspaper, the merits and demerits of this approach were discussed at great length. Whether such a method would compromise the integrity of mentally retarded persons, or whether it could be presented in such a way as to be respectfully received, were questions that were debated well into many nights. The eventual decision to utilize "want ads" was primarily based upon the belief that, if worded properly, the message would communicate that the advertisement was for a job and not benevolence.

publicity

The experiment was an unqualified success. After more than three years since the first ad was placed, 65 percent of all new foster parents continue to be recruited by this same technique. To the present day, on the same pages where exciting new positions are announced in accounting, nursing, sales and skilled trades the following type of message appears:

> "As a foster parent you can,
> Be part of an individual's growth,
> Work in your own home,
> Earn $300 to $900 per month,
> Contact the Macomb-Oakland Regional Center,
> 286-8400"

screening applicants

The absence of "mental retardation" within the text of the ad is quite deliberate. The reason for the omission is that it gives recruitment workers an important opportunity to talk with people who might otherwise avoid making an inquiry because of misconceptions about mental retardation. This opportunity is very beneficial in that it allows the time and place for painting an accurate description of both mentally retarded persons and the responsibilities which are a part of being a foster parent. When someone responding to the ad relates that their real interest lies with infants, juvenile delinquents or other groups with similar needs, the caller is helped in making a referral to the appropriate agency.

While some question might be raised about the matter of emphasizing monetary advantages to foster care, the emphasis has served an important purpose. The individual giving thought to participating in the community training home program should be aware of the positive elements from the earliest possible moment. The strains, demands and the general difficulties of working with retarded persons will, undoubtedly, occur to the interested party without coaxing. Too often the introduction to this kind of program has been by way of its difficulty and its privation requirements rather than its benefits. Experience has shown that people who enjoy the monetary rewards of the job can also make good foster parents. Simply wanting to earn money for a job well done is not necessarily mercenary nor distasteful. By thoroughly screening applicants and stringently monitoring each operating home thereafter, those individuals who are attracted to foster care only because of the money are easily identified and excluded from participation.

While classified ads have been most effective of all techniques, several others have brought positive results as well. The others presented here have also been consistently productive.

Adoption Agencies

Communication is maintained with adoption agencies so that foster care for retarded children or adults may also be considered by individuals inquiring about adoption. Many restrictions which eliminate adoptive parent applicants (e.g., couples over 40) are not necessarily grounds for elimination for foster care.

Public Service Announcements

The Federal Communication Commission strongly persuades radio broadcasting stations to air public service announcements free of charge. These announcements must have the best interest of the community in mind. The Macomb-Oakland Regional Center calls on area stations to use advertisements for foster parents. To assist the station, announcements are written, and sometimes read, by agency staff. A variety of announcements are provided, differing in time (i.e., 10, 30 and 60 second spots) and are always well written, being succinct as well as interesting. This approach has resulted in good relations with the broadcast media and numerous follow-up calls to the advertisements.

news media

Bulletins and Posters

Contacts have been maintained with a number of school systems for purposes of informing personnel about community placement efforts. Bulletins and posters describing the opportunities in community training homes are periodically distributed to public and private schools where they are circulated and/or displayed. The response to such initiatives, while not being large in number, has resulted in several outstanding placements. Posters have also been circulated to libraries and generic service agencies, such as Big Brothers, with similar results.

Foster Parent Referrals

Foster parents are approached from time to time to ascertain whether or not they might know of new potential participants for the program. While this has been an unpredictable source of referral, it has made positive contributions.

Information Booths

Education and information about the Macomb-Oakland Regional Center in general, and foster care opportunities in particular, are occasionally disseminated from booths within shopping malls, art shows, antique fairs and other similar gatherings. A short slide and audio presentation is part of the package. Descriptive material is passed out to people who show an interest, with follow-up contacts available afterward. This approach has proven worthy of the effort for community training home recruitment. While there is no supporting empirical data, the information shared in this manner with the public about mental retardation and normalization trends appears to positively affect attitudes.

Natural Parents

Communications have been made with natural parents of retarded persons to inquire about possible interest in being a foster parent. Though it may initially seem like a very remote likelihood, some parents have joined the program. The fact that they have learned much about developmental growth and behavior modification, among other topics. and generally are confident of their skills in working with mentally retarded persons makes some parents good candidates for community training home participation. They likewise respond favorably to the opportunity to introduce a new member of the household as a companion to their son or daughter. This method has produced limited but high quality results.

Articles

Each year an average of over 100 separate Macomb-Oakland Regional Center news stories appear in local newspapers. While most of these stories focus upon some new development within the agency, many highlight community placement. Invariably with each of these articles there is an opportunity to speak with the reporter preparing the story. Such contact affords good opportunity to give information about the campaign for foster parent recruitment, positive community training home features and the successful adjustments of clients who have reentered the greater community. On numerous occasions extensive articles have been exclusively devoted to the variety of challenges and rewards inherent to the foster care program. Again, as with so many other approaches, the gains are measured in positive changes in public attitudes as well as new homes.

Miscellaneous

Several techniques have been used which are aimed at large undifferentiated audiences. The information given here is always extremely short and to the point. Bumper stickers with the simple message: "FOSTER CARE, CALL 286-8400" have been modestly successful in stimulating interest in the program. Billboards and electric signs have also carried similar advertisements with like results. Television appearances on talk shows have been very reinforcing to the participating staff and also important for generally educating the public about current trends in the field of mental retardation, as well as generating interest in the community training home program.

FOSTER PARENT QUALIFICATIONS

evaluating applicants

The licensing requirements for foster parents in the community training home program are both objective, i.e., "a home shall not be licensed in which any member of the household is mentally ill or on convalescent status from a mental hospital,"[5] and interpretive, i.e., "members of the family shall be of good character."[6] Likewise the physical structure of the home must undergo similar objective and interpretive evaluation.

In many respects the more important requirements are the interpretive ones directed toward the applicant. Here the individual development staff member has the responsibility for determining the relative "quality" of the applicant and the personal characteristics of the entire household. While there are a number of individually preferred ways of proceeding in the task of screening potential foster parents, the process itself is extremely demanding. Aside from initial contacts with a person interested in the program, at least three to four visits are made to the applicant's home. The purpose of these visits is as much to observe family interaction as it is to verify square footage requirements. The following discussion highlights interpretive areas which home development staff feel are essential to evaluating a foster parent applicant.*

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[5] Rules for Licensing: Foster Family Homes and Foster Family Group Homes. Lansing, Michigan: State of Michigan, Department of Social Services, March 1975. R. 400.195.

[6] Rules for Licensing: Foster Family Homes and Foster Family Group Homes. Lansing, Michigan: State of Michigan, Department of Social Services, March 1975. R. 400.193.

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*Much of this discussion on Basic Qualifications for Community Training Home Program for foster parents was written with Urbano Censoni, M.A., and David Evans, M.A.T., and previously appeared in the Community Placement Plan for the members of the Willowbrook Plan in NYSARC and Parisi vs. Carey. Prepared under the direction of the Willowbrook Review Panel, Jas. Clements, Chairman, p. 135-7, 1976.

Some of the desirable characteristics to be considered are: patience, adaptability, understanding, warmth, openmindedness, acceptance, maturity and stability. Other factors to be considered should include physical aspects of the home itself; i.e., housekeeping habits, environmental enrichment, pleasantness of atmosphere and degree of organization. Location should be considered to be assured that there is an easy access to community recreational facilities, churches, stores, schools, employment opportunities and similar integrative sites. In general terms, the development staff worker should determine:

- Why an individual is interested in foster care; i.e., the reason for motivation.
- Whether the individual has had any previous exposure to or experience in providing similar services and, if so, in what capacity? Whether individuals have ever been licensed in the past for foster or day care. Was the service up to high standard?
- Whether there are certain preferences as to the degree of handicap the family is able to accept in the new member of their home (e.g., complete mobility, expressive language, self-care skills). Is the family able to deal with a person who has a secondary handicap?
- What are the applicant's expectations of the individual who will be the new resident in his or her home?
- What methods of discipline are used in the home? Is the applicant willing to refrain from using physical punishment with a new resident, even though it is used with his or her own children?
- Whether the individual is consistent in handling his or her own affairs. Is the applicant considerate to others, dependable, etc.?
- Whether the individual is willing to learn how to be an outstanding foster parent. Is he or she apt to look forward to education/training sessions and seek to gain from them?
- Whether the individual deals with present family members in an appropriate manner. How flexible is the applicant when things are not going well?
- Would the potential foster family have any reservations about taking a resident with them on shopping trips, recreational outings, restaurants? How would foster parents react to negative comments by others? How difficult would the adjustment be for other family members?
- Whether the applicants would react responsibly in a crisis situation? Would they tend to be overprotective?

- Whether the family could make a contribution of time and energy to the life of a new member.

While the varied recruitment approaches interest large numbers of people in the community training home program, very few individuals are actually accepted. In the words of an experienced development staff member: "We interview individuals who are applying for a rewarding, important yet extremely demanding job. We look for people who are able to raise adults not children. People like that are not easy to find."[7]

CONSULTANT STAFF

team approach

In order to assure foster parents and clients of appropriate professional follow-along support a team of consultants is available to exclusively serve the community placement programs. This team consists of a variety of disciplines built around physician, nurse, psychologist and educator. While individual consultants do provide direct service when necessary, they also spend considerable time in establishing and maintaining contacts with their professional counterparts in the community. All community training home residents, for example, have their own "family" physicians in the community, who serve the mentally retarded patient as they would any other patient. The physician also is aware that any assistance he or she might desire is available through the Macomb-Oakland Regional Center medical consultant.

consultation

By making consultants accessible for in-home programming and foster parent training the client is assured quality follow-along. By making themselves available for referral the consultants help the client integration process by supporting service acquisition from community-based resources. Each of these assurances brought by the consultant group results in the foster parent feeling more secure in backup and better directed in their contribution of room, board, supervision and in-house programming.

CONCLUSION

When examining the strengths and limitations of the community training home it is understood that inevitably someone will detract from design or structure. With this, as any other model, one hundred reasons can be given for weakness and for the concept being unworkable. The fact of the matter is, however, that it has worked and worked well.

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[7] Roberts, S. Macomb-Oakland Regional Center Development Staff Supervisor. Discussion on foster parent requirements. Mt. Clemens, Michigan, November 10, 1976.

In the three and one-half years since the Macomb-Oakland Regional Center refurbished the traditional foster home model, over 175 community training homes have been developed. At the present time there are over 184 children and adults living in some 135 placements. Clients here vary in level of handicap from mild to profoundly retarded, with 50 percent being in the severe range.

The linking of payment for in-house program contractual agreements, skills training and close monitoring procedures have in combination unequivocally expanded the versatility of this variation of the foster home. Over 34 percent of all individuals initially seeking institutional admission receive preferable placements in community training homes instead. For these people the institutional step is thus eliminated altogether.

Specialization of recruitment roles and marketing, rather than charity-like approaches, has resulted in the home development staff having the luxury of being so selective as to accept only one out of every 30 initial applicants.

The limitations, stated earlier as being frequently pointed out by professionals, are not resolved in every community training home. There have been individual home failures, and clients have had to be moved. Such occurrences are extremely rare, however, and the percentages would indicate that placements are well worth the risk.

Natural parents and guardians have become so accepting of the program that after visitations with foster parents in their individual community training home and a review of all the features of the program rejection of the placement is virtually non-existent.

In the Macomb-Oakland Regional Center hierarchy of institutional alternatives the community training home is not in last but first place in numbers of clients in residence. It is also viewed most often as the preferred option outside of the natural home.

The community training home is certainly not the single answer to community placement. Much more work must be directed toward supporting natural home living, and additional models for specialized living arrangements are obviously required before we can even begin to get within reaching distance of any ideal answers.

Our experience with the community training home model has proven it to be a desirable normative setting, adaptable to a multiplicity of needs. Much of the model's potential as a promising residential alternative lies within this capacity to be both versatile to the agency and sensitive to the individual.

DMH-1218

COMMUNITY PLACEMENT PROGRAM DESCRIPTION

Completion Instructions
on Back of White Copy

Appendix I

1. Check Facility Type - ☐ Foster Family Care ☐ Community Living	2. No. Beds Contracted -	3. No. Residents on This Program -
4. Agency Name		5. Agency Code
6. Home/Facility Name		7. Home/Facility Code

8. General Description of Home/Facility -

9. Characteristics of Residents Being Served -

10. Specific Program Objectives -

11. Activities and/or Services of Program (Specify Estimated Time for Each)
   A. Provided Through This Contract -

   B. Provided by Other Community Agencies (ISD, 54REL, ETC.) -

12. Per Diem Costs for Activities and/or Services Listed in Sect. 11.A. Above -

Activity/Service	Hours Per Time Period	Rate Per Time Period	Per Diem Rate

Total Per Diem Rate

13. Supervision (Specify Evaluation Procedures to Monitor Above Activities/Services) -

Blue Copy - Central Office Green Copy - Agency White Copy - Manager 06-01-73

MICHIGAN DEPARTMENT OF MENTAL HEALTH

APPENDIX I

COMMUNITY PLACEMENT

CONTRACT TO OPERATE A ☐ FOSTER FAMILY CARE HOME or ☐ COMMUNITY LIVING FACILITY

CONTRACT STATUS: ☐ NEW ☐ RE-NEWAL ☐ RE-OPEN ☐ CHANGE OR CORRECTION

The Michigan Department of Mental Health and its constituent

(Agency Name and Code)

hereinafter referred to as the Department, and

(Home or Facility Name)

(Number and Street)

(City) *(State)* *(Zip Code)*

(County) *(County Code)*

(Home or Facility Number) *(No. Beds Contracted)*

the Manager of a Foster Family Care Home or a Community Living Facility, hereinafter referred to as the Home or Facility, agree:

1. *That the Home or Facility shall provide services for placed residents according to the conditions of this contract and published rules, policies, standards and procedures of the Department relative to Foster Family Care or Community Living Placement. A description of Program Activity must be attached.*

2. *That reimbursement by the Department to the Home or Facility shall be:*

Basic care $
Personal Allowance
Program Activity Allowance
Total Per Diem Rate $

3. *That this contract may be terminated by either party without cause upon thirty (30) days notice in writing.*

4. *That this contract shall be in force for the period beginning* *Date* *through June 30, 19*

Signed *(Manager)* *Date*

Signed *(Agency Representative)* *Date*

Approved *(Agency Superintendent)* *Date*

* *Supply name and/or address if check payee is different from above.*

(Payee Name)

(Number and Street)

(City) *(State)* *(Zip Code)*

Central Office
Blue Copy

Agency
Green Copy

Manager
White Copy

DMH 1018 (5/72)

APPENDIX II

Any Item not completed must be explained

Case Number ____________

COMMUNITY TRAINING HOME MONTHLY PROGRESS REPORT
(M.O.R.C.)

Resident's Name ______________________________ Month/Year ______________________________

Home Operator ______________________________ Height: ___ Ft. ___ In. Weight: ___ lbs.

PROGRAM OBJECTIVES (list as in Program Description, e.g., self-care, dressing, and specify as necessary; e.g., learning to tie shoes)	Objective Completed	Improving	No Change	Consultation Needed
1.				
2.				
3.				
4.				
5.				

Describe any changes in behavior or unusual incidents that have occurred in the past month. (Please be specific, i.e., illness, temper tantrum, runaway, etc. ______________________________

What is (are) the resident's immediate need(s)? (Be specific; speech, toileting, different program, etc.)

Do you need training or specific information in any program area? If so, which area? ____________

Doctor, Dentist, Therapists or other Professional Contacts	Name ____________ Date __ __ __	Reason ____________
	Speciality ____________	Treatment ____________
	Name ____________ Date __ __ __	Reason ____________
	Speciality ____________	Treatment ____________
	Name ____________ Date __ __ __	Reason ____________
		Treatment ____________

Please list current medications:	Type (i.e., Dilantin)	Amount (i.e., 5 milligrams)	Frequency (3 times per day)
	1. ____________	____________	____________
	2. ____________	____________	____________
	3. ____________	____________	____________
	4. ____________	____________	____________
	5. ____________	____________	____________

Were any of these medications changed in type, amount or frequency, during the past month? Yes ___ No ___

If yes, what was the change? ____________

Who ordered the change? ____________

Do you believe current amounts of medications are appropriate? Yes ___ No ___

If no, please explain: ____________

Social and Recreational Contacts:

1. ____________	7. ____________
2. ____________	8. ____________
3. ____________	9. ____________
4. ____________	10. ____________
5. ____________	11. ____________
6. ____________	12. ____________

Have you had contact with the school or workshop? ____________ If yes, Describe ____________

____

____

Have you had any contact with the resident's family or guardian? ________ If yes, how many? ________

Did the resident's family or guardian visit during the month? ________ If yes, how often? ________

Was the resident employed at anytime during the month? ________ If yes, where? ________

Was the resident informed as to his progress in reaching program goals for this month? ____ Yes ____ No

By whom, (i.e., Home operator, social worker) ____________

Are you presently satisfied with any or all aspects of the Community Training Home Program:

1. Very Satisfied ______ 2. Satisfied ______ 3. Not Satisfied ______ 4. Very Dissatisfied ______

Please explain if 3 or 4 were checked:

____

____

____

The Village

Innisfree Village

HEINZ KRAMP

In 1971, on a four hundred acre farm adjacent to the Shenandoah National Forest in the foothills of the Blue Ridge Mountains of Virginia, a community called Innisfree Village came into being. The name comes from the Yeats poem in which a primal and profound song draws the poet to an island of peace--a sensation bound closely to the passing day's beauty of sound, color and light. The Village was formed as Innisfree, Inc., a tax exempt, charitable and educational public foundation to provide, in many cases, a life-span facility for mentally handicapped adults. Dedicated to creating an environment where volunteer workers would live and work with mentally handicapped adults eighteen and over, the Village grew from a few workers, their families and two villagers (a term used to distinguish the mentally handicapped) to a community that is now inhabited by 30 villagers and 20 co-workers and their children. The basic intention behind Innisfree's creation was to provide a home environment that would foster the development of the mentally handicapped person and lead him on a course where his full potential as a human being would be actualized. Decisions by the Village's management are made in response to this obligation.

The purpose of this discussion is not to trace the historical development of Innisfree, which would cover the evolution of the community sociologically, economically, ethically and in every other way in which a society grows, but rather to try and delineate those elements within this intentional society which act as catalytic agents for growth. The importance of this kind of theoretical identification lies in the possibility of replications of the village model in different locations and across a span of time.

farm community

Several premises governed Innisfree's beginnings, and they all attest to the fact that society was not meeting the needs of the adult retarded, brain-damaged, autistic or chronic schizophrenic person. Either he was shunted off to near "non-existence" in a large institutional setting, or he found himself confined in a narrow world of home, a prisoner of his family's embarrassment and overprotectiveness - an adult condemned to a child's life. In some cases he found employment and an independent living situation, but one that was bereft of social contacts and meaning. A new kind of society was envisioned by the founders of Innisfree; one which would be somewhat removed from the hectic flux and flow of modern urban life. Specifically, a farm community was begun where there was more time, more freedom of movement, more directness of rewards, but also where the number of conflicting stimuli were considerably reduced.

organizations

The Corporation has a Board of Directors whose selection is based on their interest and background in the field of non-institutional care of mentally handicapped individuals. The Board is responsible for establishing policies and overall guidance of the Village, including capital and operational financing, general administration and the admission procedures for villagers and co-workers. The Board elects corporate officers to fulfill the responsibilities of President, Vice President, Secretary and Treasurer and has created an Executive Committee consisting of several Board members who are authorized to act on behalf of the Board.

The Village has an Advisory Board whose members are highly qualified in several medical and psychiatric disciplines, and their professional counseling has been of inestimable help to the Village.

Day-to-day administration is delegated to the Executive Director and the Assistant Director, who are responsible to the Board for the operation of the Village. Clearly, the fundamental obligation of the Village is to serve its residents, demonstrating that this pioneering effort is a small but viable response to a problem of immense proportions.

approvals

It is important that one is aware that the Village has had to obtain, and must maintain, authorization and approval from federal, state and local governmental agencies. These approvals, which are manifestly essential to the continuation of the work of the Village, are subject to regular and close review by the granting agency which has the right and, in fact, quite regularly exercises the right, to modify the terms and conditions of their continued approval of Innisfree's operation. We are pleased and proud that the Village has been successful in meeting the requirements of the various taxing and licensing offices that permit us to operate, and it is obvious that our continued operation requires compliance with all future requirements of these agencies.

benefactors

Another important constituency to which Innisfree has a continuing obligation is that group of benefactors whose generous economic support has allowed the Village to create an outstanding physical plant as well as to support the significant annual operating deficits that have occurred each year since its founding. While we are most grateful for this past support, we are acutely aware that the Village must continue to attract contributions and grants to create scholarships, to reduce its present debt level and to provide facilities to permit the continuing development of the Village.

family units

shared work

The Village, as it is today, consists of a number of self-contained living units; in some, villagers and co-workers live as fully functioning extended family units sharing all household chores and responsibilities; in others, co-workers or villagers live in separate smaller houses, functioning independently but offering each other mutual support when needed. Everyone in the Village shares in the work of the community: in the weavery, where serapis, mats and blankets are woven; in the bakery, where 1,500 loaves of bread can be baked each week; in the woodworking shop, where wooden toys and furniture are constructed; or on the farm and in the gardens, where much of the food used by the Village is raised. One of the goals of the community is to move toward greater economic self-sufficiency. The Village has a director, who is also the co-founder of the community, a governing committee with a rotating membership of villagers and co-workers and committees for various functions of work and life in the Village. Social life is varied and active both in the Village and in the nearby communities, involving folk dancing, hiking, play reading, dances, etc.

co-workers

The key to Innisfree's continued development is its ability to attract and retain a group of dedicated co-workers who combine a concern for the handicapped with a desire to contribute all of their talents to the challenge of creating an environment that best meets the needs of our handicapped villagers. Working with the handicapped can be emotionally draining but, at the same time, the rewards of helping another climb the ladder of dignity and self-worth can be tremendous.

The serious responsibilities that are assumed by each co-worker warrant an intensive analysis of each candidate's maturity, motivation and ability to cope with a wide range of challenging problems on a continuing basis before a commitment is offered or accepted.

A prospective co-worker should be aware that while a large measure of self-governance is encouraged through several co-worker committees, guidelines

the obligations of the Village to its various constituencies necessitate the observance of certain guidelines. These are designed to assure conformance with standards that are normal in the field of non-medical residential care of handicapped persons, as well as to provide reasonable solutions to administrative problems that have occurred as the Village grew.

commitment to serve

A co-worker's decision to come to Innisfree is made only after a month's trial period at the Village has been successfully completed and implies agreement to conform to the guidelines of the Village, including:

- An accepted co-worker is expected to make a commitment to serve the community for at least one year.
- Co-workers are entitled to three weeks' vacation during the year. It is expected that one week of vacation will be taken approximately 90 days after arrival and the balance after six months at the Village. The Village must always be adequately staffed and vacations desired during the Village holiday periods (Spring, Thanksgiving and Christmas) must be coordinated within the community to assure that enough assistance is always available to meet the requirements of the villagers who remain at Innisfree during these periods.
- Co-workers are provided with food, clothing, personal incidentals and lodging under the prevailing budgetary allowance; Blue Cross-Blue Shield medical insurance, $10 a day while on vacation and a severance allowance of $25 per month, which accrues and is paid only after six months of service, when the co-worker leaves the Village.
- The Village's responsibilities as a long-term residential care facility require close coordination between house parents, the Village's Director, professional advisors and the parents or guardians in all decisions that might affect the villager's development and progress.

hierarchy of needs

A description of this kind is only cursory but does offer a background on which the particular growth inducing elements can be illuminated. In moving through a hierarchy of needs [1] it is established that once the individual's physical needs are met and his relative security assured, the whole area of the need for meaningful employment and the need for love come into focus. These basic needs are universal: with the handicapped person they are often unmet needs. The effect of meeting these needs has had a dramatic effect on the lives of the people at Innisfree. Though the mentally handicapped person has greater needs for immediate meaning to whatever he does, many work situations for the handicapped individual involve meaningless, repetitious tasks. The villager who bakes bread in the morning at Innisfree sees it on the table at the evening meal; if he or she weaves a blanket, it will probably also be sold at the local crafts fair. The house he lives in will probably have nails which he has pounded into the walls. There is a definite sense of immediacy and of being a cause in the total environment. A sense of pride is developed in seeing the community grow because of the individual's effort. This spills over into the whole category of need for love, approval and relationships. Innisfree offers, in its supportive environment, a place where the handicapped person can develop dyadic relationships in a purposeful way so that he enriches the lives of the people concerned and those around him. The villager also experiences the fact that he is a person valued by a whole community of people for being himself. His development of self-worth grows as he hears his own voice in Village meetings and his suggestions being implemented into actions. As he walks the two to five miles around the Village that his daily routine of work, rest and socializing requires, his body becomes stronger and his initiative is reinforced. Most handicapped persons who have come to Innisfree have never experienced the "right" to visit their neighbors or to transport themselves to where they needed to go. The freedom of movement around the Village again enhances the need of the person to be effective; literally to be able to effect where his body will move and the choice, decision and subsequent implementation that involves. In Maslow's hierarchy, the villager might be fulfilling a lot of his higher needs for self-actualization through simple actions, such as going to see a friend down the road after dinner.

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[1] Maslow, Abraham H. Toward a Psychology of Being. 2nd Ed. New York: D. Van Nostrand Co. 1968.

self-image

freedom
to learn

The dramatic growth and development noted over time in the people who come to Innisfree can be attributed partially to the physical and structural factors that constitute the community. Certainly the intensely beautiful setting, the woods and farmland and the mountains contribute, as do the attractive houses, the simplicity of work and the relatively uncomplicated nature of a life which is somewhat like a nineteenth century rural community. However, what distinguishes the thinking that shapes Innisfree's impact on the individual?

Innisfree grows out of the tradition of milieu therapy and Maxwell Jones' notion of the therapeutic community.[2] The emphasis on the sheltered aspect of the environment and the importance of allowing the individual freedom to influence his world are common to all three approaches. Implicit in Jones' theory is the idea that the traditional hospital, or other institu-

milieu therapy

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[2] Jones, Maxwell. Social Psychiatry in Practice: The Idea of Therapeutic Community. Baltimore, Md.: Penquin Books Ltd. 1968.

tion, robs the individual of his right to choose, to effect, to initiate, to become and, in fact, his right to be. In the sense that Innisfree provides a total environment it goes beyond the concepts of the therapeutic community. Jones points out that any hospital, and most institutions, suffer from the hierarchical, authoritarian nature of the training of the professionals involved whenever any attempt is made to create a democratic, therapeutic milieu. Innisfree's co-workers, as non-professionals, have not been preconditioned into this authoritarian mold, and this has allowed the development of a democratic therapeutic atmosphere. The point to be emphasized here is that Innisfree comes out of, but is different from, the traditional concept of therapeutic communities.

holistic
involvement

The most salient factor of the theoretical framework underlying Innisfree seems to be that it is a total society involving the person in it in a holistic way. It is implied in other therapeutic communities that there will be intervention strategies at particular times. Here the intervention is continual, woven intricately into 24 hours of the day. Secondly, the villager contributes to his own program through being involved in a living situation which allows him room to grow. Since the co-workers are not professionals, resources for "treatment" come from an interweaving of individual and community needs. A constant regenerative inventiveness is required by life experiences which are always changing. The continuing change in living arrangements exemplifies this idea. Another way of expressing this notion is that the person at Innisfree is involved in shaping the community at all levels, therapeutically, sociologically, politically and economically.

structure for
growth

Arising from but being more than any of these other ideas is the fact that the theory is open--its gestalt is always changing even though ideas are basically arrived at through empirical observations. As the villager learns new physical and social skills, the patterns of his or her relationships change. An open and democratic social structure evolves naturally from this growth. Movement is seen, within the individual and the community, from a need for authoritarian structure to a self-expressive, democratic mode; also, movement from a supportive, sheltered environment of living toward one which involves risk taking. The community sets up new situations as new growth needs demand them.

stability

Another precept underscores Innisfree's long-range aspect. The stability and persistence inherent in the fact that many people come to live at Innisfree for the rest of their lives is quite important. Some people, of course, become capable of returning to live in the greater community, but they are also strongly affected by this stability factor. Another of the powerful forces toward self-actualization in the Village lies in the fact that everything that happens affects everyone else in the same way.

The sense of inclusion and interresponsibility affects even the non-verbal people, since communication will occur through multiple contacts in many situations.

research potential

The nature of the ideas just discussed is certainly heuristic. Innisfree would be a logical and exciting place to start a longitudinal growth study: to identify where people were when they started; how they developed; and to begin to validate (or refute) what factors are growth inducing in this particular environment. There are some interesting observations which serve as a point of departure for anyone interested in such a project:

sense of identity

- People come to Innisfree with what we will call, for lack of a better term, a repressed sense of their own identity. After about a year and a half in the Village there is a strong surge toward establishing and exploring that identity. This involves sexual, social and work attitudes.
- After a short period of time a marked decrease in medical problems is observed.

health

- There is a marked reduction of tension. The most dramatic evidence of this is the consistent reduction of epileptic seizures, in both frequency and severity (one-third of the villagers are epileptic).
- There is marked improvement in the physical posture, the mobility and often the appearance of villagers.
- There is a marked reduction in the need for psychotropic drugs among the schizophrenic villagers. Some schizophrenics are completely off drugs.

parents

- The relationship between parents and villagers seems to change. Parents have some of their guilt alleviated in seeing their children in a conducive environment. Parents begin to see their children more as adults.

financial support

Innisfree is a private institution, supported the last five years by a few generous individuals and grants from interested foundations. Villagers must pay a monthly fee, and although it compares favorably with costs of less enlightened institutions, it is still considerable. For some of the families the amount is a severe hardship. Unfortunately, the Village is not yet solvent enough to provide scholarships based solely on financial need. Hopefully, Innisfree will prove its success and validity to enough foundations and private institutions which will provide greater financial support.

Our goal is to be accepted for who we are, without labels that restrict or apologize for us. The handicapped men and women are striving hard to prove themselves capable and worthy of society's respect. One strong ambition is to be considered competent and responsible, a model and teacher, a co-worker. Some day, and the day is inevitable, the Village will rid itself of labels. Some day, too, every person there will become a co-worker because recognition will come that everyone is at Innisfree for the same purpose--to prove fundamentals about himself which are positive and affirming.

Mental handicap is not viewed as a handicap of the whole person. Rather, the natural unfolding of the individual as a social, emotional, creative being is seen to take place when extraordinary pressures are relieved. In this paper we have attempted to identify some of the theoretical background of this community, whose avowed intention is to foster and develop the maximum potential of a certain segment of our population.

Summary and Trends

FRANK J. MENOLASCINO

Summary

It is my task to summarize the key elements of this two-day Forum on Residential Services. Recent court decisions, accreditation standards and federal regulations are mandating a reduction of the current population in large public institutions--along with major improvements in the quality of all residential programs. A lack of adequately described alternative residential models places state planners and consumer advocates in a position of making poorly informed decisions. State agencies have frequently committed enormous resources to residential service plans which later prove ineffective, disruptive, contradictory and, in some cases, illegal because the planners did not have access to the volume of reliable and appropriate alternative service model options. The overriding hope of this conference was that its format and content be correctly designed so as to have maximum impact on the problems and dilemmas faced by state and local planners of residential services for our mentally retarded citizens.

This overall goal was addressed by providing the basic information necessary to develop action plans for implementing a comprehensive system of residential services; showcases were utilized to both illustrate and discuss better models--which embody the elements of this planning approach. It is a tribute to Eleanor Elkin, Chairperson of our NARC Residential Services Committee, and Gene Patterson, our NARC residential staff resource, and the kindness of a contributor to our national ARC movement that this Residential Forum has been able to directly address itself to these readily apparent needs.

forum goals

NARC history

This Forum's proceedings were opened by some free associations by myself, and then Eleanor presented an eloquent overview of the evolution of past and current NARC residential service policy statements. She sharply underscored the fact that in the late sixties there was a major turn-around of our NARC movement. She noted that, in the fifties and early sixties, we had tried to improve the institutions in every way possible and, despite our persistent efforts, there came the sobering awareness that we had to seek viable alternatives outside of the traditional public institutional setting. Eleanor reviewed some of our past NARC residential policy statements from the sixties, and they sounded as if they could have been issued last year, yesterday or today--sobering, very sobering.

policy statements

She reminded us that our ARC movement's residential policy statement in Montreal (i.e., that there should be no residential construction on the grounds of current public institutions for the retarded in this country) produced much gnashing of teeth among many individuals and groups in our country. Much of this turmoil was also experienced by our own ARC units--they had residential expansion programs on the planning board, political agreements to be consummated, edifices were to go up--but Montreal's policy statement went straight through all of these mixed expectations. During this Forum we have clearly noted that despite the Montreal policy there has been an end-run. Yes, there have not been any appreciable numbers of new residential beds at the old institutions; instead, there have been many new small institutions erected elsewhere. Essentially an end-run around our Montreal policy statement has been accomplished.

continuum of service

John McGee discussed in his presentation the pressing need to closely examine what we do in our current and future provisions for residential alternatives--and why. More specifically, he spoke of a sliding continuum of services: from least to most restrictive environments and allied program goals. One of the illustrations he utilized showed us very clearly that in this sliding continuum there are also sliding expectations. The more you went to the right on the continuum the less restrictive was the living environment and more developmental opportunities were provided to the retarded citizen. He also stressed the crucial role of the family in providing these opportunities. Indeed, the issues are not restricted to the states that John mentioned--they are issues and challenges which occur across our country in state after state. It went through my mind that this young man is really quite "old" in some of his views. He spoke of our need to continually stress the dignity of people, including the central need to provide effective support systems for the family units in our society--especially for someone the sociologists label as "deviant." He stressed that we should scratch this and other labels and talk about fellow citizens who have an inalienable right to developmentally-oriented programs within least restrictive settings which fully embody the program principles of normalization. He noted that professionals must continually commit themselves to self-examination of whether their programs truly embody the sliding continuum of program ingredients within the associated dimension of higher or lower program expectations.

institutional populations

During the luncheon session Fred Krause gave a fine but rather perplexing presentation. I saw Fred's overheads on the decreasing population of the large public institutions; there was also visual proof that the number of facilities have increased--lowered populations in a greater number of institutions. The overhead visual demonstrations brought back the residential data I viewed in the Fall of 1971 when, for the first time in almost seven decades in this country, there were more discharges than admissions to the large public institutions for the mentally retarded. First time in 68 years! And now we have built smaller places for them to reside.

financial support

Fred also reviewed recent data on the "levels" of the symptom of retardation in the retarded citizens who still reside in the large institutions: the majority are severely retarded individuals with multiple handicaps. Equally disturbing was Fred's graph which clearly showed that 15 of each 16 dollars spent in residential services for our retarded citizens still continue to go to support the large public institutions. No matter how you move these financial figures around they are still going to the historical backbone of the care for the retarded in this country: the public institutions; and the community-based residential programs literally have to beg for the financial scraps that are left over. Despite the ongoing efforts of Doris Haar, who attended this Forum, and has effectively tried to help parents and local communities in that begging, the actual dollars currently available for community-based residential alternatives are still scraps.

need for service

The levels of mental retardation usually cited as the "really difficult" clinical and residential challenges are the severely retarded. When I first became involved in this field we spoke of the borderline, the mild, the moderate and the severely retarded. Today I repetitiously see captions that only talk about the severely retarded and multiply handicapped--and they are typically viewed as "today's hopeless ones." Less and less do we hear of the moderately retarded and most professionals agree that the borderline label should be discarded, and the mildly retarded should never have gone to the institutions in the first place. The overfocus on today's "hopeless" retarded citizens (i.e., the severely retarded), though a myth, has been utilized to defend the public institutions because "They belong there since they are the hardest to serve." Think about it.

priorities
for service

No one talks about the borderline and the mildly retarded any more--perhaps out of professional guilt because they never should have been there in the first place. Many of the severely retarded in the institutions, we are told, are quite old in chronological age, and I've had individuals tell me, "You know, Frank, the adults in the institutions are indeed the lost generation." The suggestion is that we should turn our backs on them and focus on the severely handicapped children. Nothing new. For example, a white paper came out in England two years ago--same kind of view--take care of the handicapped kids in the community by demanding that no individual under 12 years of age be admitted to an institution for the retarded. Forget about the people over 12 years of age. That's pretty young to be considered "old!" It was the singing at Christmastime of a group of these same "old" children whom Fred Krause commented on in regards to his past experiences as a staff member at the Dixon State School. They are the biblical children in the wilderness, and I think this type of "singing" drove Fred from Illinois to our Associations for Retarded Citizens' movement and now to his position with the President's Committee on Mental Retardation. I think he's done a darn good job, though he can never forget the voices of those "old" children who still plead for help in Illinois and the other 49 states of this country.

funding
resources

In her presentation Rita Charron did a most admirable job. This lady has had a "noble obsession" to figure out the complexities of federal funding--especially as it relates to residential alternatives. It is not a pathological obsession, but it darn near makes you pathological when you must master the current 90-plus funding sources available for residential programming. Rita brought together and shared with us the expertise of a CPA, program person, an advocate and a person who knows how to get money. Be quick on your feet, quick of mind, don't drink, perpetually stay awake--and somehow you can figure out the entanglements of how to get money to provide modern residential services! I keep hearing about "audit-trails" and others talk about "audit-tracks," and now we are about to embrace "zero budgeting." However, we still have the overriding issue of does the money actually follow the retarded citizens? When you are all done with those trails and tracks--out there in that financial wilderness--many creative suggestions for fruitfully utilizing money for residential programs for our retarded citizens have come forth over the years. Many of the financial suggestions have been quickly labeled as crazy or simple-minded or both. For example, about eight years ago, someone said to me, "You know, Frank, why not depopulate the overcrowded institutions (that was the word then, depopulate--we now have deinstitutionalize, and I suspect that the "in" word will soon be decentralize) by giving the daily cost of care of a client to each employee who will take one child home to care for him in his or her family." Similarly, a colleague asked, "Hey, why don't we take that per diem cost and give it to the primary family to take the child home?" Maybe $10,000 a year (the usual minimal cost of care for such an individual in the public institutions) for a severely retarded youngster is considered peanuts in your state, but $10,000 is a lot to a farmer in mid-Nebraska who works hard, wants his child (i.e., most often they have sent their child to an institution as a last resort)--and give him the $10,000 and the programmatic knowledge (which we can now package so well) and let him serve his child. Interesting? Simple-minded? Perhaps! I mention these two options to you because, as Rita noted, the issue of actually providing modern care is not that complex, if you can obtain the money to literally get it done!

funding options

Dennis Popp spoke of the need for administrative and programmatic excellence. He stressed that we must put these two entities together because the cost-benefit approach is not the only "bottom line" approach to serving people. On the contrary, we must utilize the dollars in a creative sense in conjunction with objective criteria for the actual delineation of costs for whatever the level or type of retardation. He specifically discussed the evolving modern systems approaches and how they can be effectively utilized. We should take his presentation very much to heart since we have noted, in state after state, governors calling in consultant firms (who tend to know precious little concerning service systems for the retarded). Their usual two-volume reports say, yes, it justifies the $80,000-plus you paid us for vague guidelines that are not referrable to the mixed financial-programmatic challenges present. Familiar posture? Instead, Dennis clearly illustrated that specific cost-service benefit guidelines can be closely wed to all aspects of program development, operation and their periodic evaluation--all along guidelines that are objective, replicable and above all: firmly encompass the humanistic posture of truly serving people. Such systems are here and, as Dennis underscored, we must utilize them "up front" in our thinking, planning and actual program operations.

administration

cost benefit

Paul Friedman, in his review of the impact of legal decisions on residential services, reminded me of one of Elizabeth Bogg's comments during a recent presentation. She defined the "medical model" as nurses talking to doctors and doctors talking only to God. Further, she described the evolving "legal model" as lawyers talking to judges and the judges only talking to God. I would commend to your attention that, as Paul noted, God is answering the judges pretty well lately! The recent benchmark cases concerning the public institutions for the retarded across our country have pricked the consciences of our people and, as recently noted in Minnesota, they have raised the question of the conscience of our state governments. We do not have to continue, as Paul mentioned, like the Partlow situation wherein the attorney had to talk about good looking cows, who are both athletic and of confederate ancestry, in order to continue

quest for justice

legal decisions

our quest for justice! It has been my pleasure for the last three and a half years to be a witness and an active participant in a case which requests equal justice for the institutionalized retarded citizens in Nebraska. I have learned a great deal about the law and feel blessed to have had that opportunity. We have a young attorney (Mr. Bruce Mason) who deeply cares about all people; a young attorney who has given over 4,000 hours of legal work free of charge to our state ARC movement. He and I recently wrote an article for the Creighton Law Review; it darn near drove me crazy since the lawyers have a way of writing articles where you write two lines and then give 75 lines of footnotes. I almost began to stutter! I would say something, and he would persistently ask, "How do you know? And then document how you really, really know." That's good training--good discipline. It was traumatic but mind expanding for me because Bruce kept saying why? Why? Paul Friedman noted that when you ask questions about the need for least restrictive residential alternatives--immediately on the heels of the right to treatment issue--you come very close to true justice for the retarded citizens of our country. You also come very close, as Paul pointed out in the Bartley v. Kremens case, of asking why we continue to commit, for an indeterminate period of time, those fellow citizens who have not sinned against anyone.

monitoring

Ed Skarnulis spoke of the key issues of monitoring our residential services, the necessity for systems to be open before they can be effectively monitored and that observations must be externalized. The guidelines for long-term residential placement present some major challenges for all of us (e.g., see the NARC Nursing Home Symposium publication). Ed candidly noted that we are not in an adversary position in regard to monitoring. Rather, it is protection of the rights of the retarded via a concern for openness. Across this country I hear people saying, "Yes, Frank, we like the ARC to monitor, but gosh they are tough! Why don't you ask them to be less hostile and more polite? We are really their friends." It reminds me of the I'm okay-you're okay paradox. As Ed spoke, I thought of an inscription on our capital building in Nebraska, "Vigilence is the price of liberty." Similarly, monitoring is the price of quality residential services for the retarded citizens in this country. In particular, we must get that message across to young parents--so many of them seem to feel that the work has already been done, that modern services will be given to their children and somehow Uncle Sam will have the conscience (or state governments will have the conscience) to provide a plentiful spectrum of quality services. That conscience is not automatically there; rather, it is embodied in the advocate who is actually armed with the knowledge and personal commitment to actively monitor--as Ms. Burda mentioned here and at our National Convention in Indianapolis.

Ed gave a splendid "How to" listing of an approach to monitoring and accountability. I was pleased to note his positive view toward the need for consumers, providers and funders to join together to keep each other honest. His quotation from Robert Frost should spur us to continue this difficult but vital work, "But I have promises to keep. And miles to go before I sleep; and miles to go before I sleep."

the village

The Showcase presentations ranged from the village model, the foster family concept, to support systems for the primary family. The village model is a humane one which has long historical roots and avid supporters for various approaches to village living. Typically, it is a rather narrow model as far as the options available for a retarded person to live within the interpersonal context of a wide variety of fellow humans. Perhaps the village's model can also encompass some of the L'Arche movement's splendid mixing of heterogenous groups of individuals--including the retarded.

foster families

The foster family presentation was an illustration of a traditional model which is great as far as providing a true family support system--though the presenter stressed how hard the professional must scratch to actually find these alternatives. Maybe, like the redirected thrust of the Roosevelt Center in New York, we can provide the residential services without the fixed bed focus. In other words, provide the services where retarded people actually live--in their homes, neighborhoods, towns and cities.

community systems

The ENCOR system of residential services, as reviewed by Barry Lamont, clearly illustrates the active incorporation of the normalization principle and the developmental model into a functioning real-life system of services. I will not comment further on the ENCOR presentation since my brain and soul have been too close to this model of services, from its inception, for me to be an objective responder to Barry's presentation. It brings back many personal memories--like asking myself in the middle sixties why the severely and profoundly retarded children are always kept in the medical-surgical units of the institution? Why are they there in their stainless steel cribs with the plastic on top and the room surrounded by wire enmeshed glass as though it were some kind of infant nursery in an acute infectious disease hospital unit? I would often ask (sincerely), "Who is sick here?" People would say, "Aren't you a 'real' doctor--these kids are sick--they have tough medical problems!" They would typically become more upset as I would persist and ask, "Who has a high temperature? Signs of inflammation? Pallor?" Nobody! We must all ask, "Why are they there?" Rather than alluding to some vague (and usually static) neuropathological process which usually translated to, "Something wrong with his brain," the issue is really that these youngsters can't "make it" without a support system for their seizures, their delayed development, etc.

They are treatable in the community and so why do we keep putting them "...with their own kind?" Why do we keep sending them away from the nurture of their own familes? They are often viewed as "not going anywhere" and so they often go to the institution for long-term storage because, "We all know they cannot grow"; "we all know there is no hope"; etc. The ENCOR system reviewed by Barry was, and is, Nebraska's direct answer to these lingering myths and negative self-fulfilling prophesies.

institutions

The more advanced institutional setting was well illustrated by the presentation on the Ludeman Center. It represents Illinois' answer as they saw the challenge in the late sixties; it was built in 1972, but conceived in the late sixties. In the film strip component of this presentation there were children singing "The Impossible Dream"--similar to the group that Fred Krause discussed. One of the mothers in the film discussed her mixed feelings about bringing her child home. The institution was not viewed as a "home" by either the mother or her daughter. I believe that the overwhelming number of institutionalized citizens truly **know** their homes and their people! The Ludeman Center was to be homelike; it was to be like a home. It was to be many steps beyond their Dixon facility and yet one must ask--why couldn't these cottages have been dispensed in the communities across Illinois? Why must we continue to build the modern leprosarium again and again? Call it whatever you want, but it ends up being a modern leprosarium because they've got the "disease," and seemingly must be herded together as a deviant group set apart from their brothers and sisters.

group homes

The group homes evolving in Pennsylvania are very interesting. Mel Knowlton spoke about going beyond the group homes, and Pennsylvania has wrestled with the challenge of actually having the money and now trying to find the way to use it effectively. It is one of the few states that has the money needed to operate and bring into being systems of relevance which everyone can live with and be proud of. I wish them well in their superb initial thrusts.

What do these Showcases tell us? One person at lunch today, who will go nameless, said, "You know, Frank, are these really showcases? It is like teaching young doctors how not to do an appendectomy." Think about that. We always teach young surgeons how to do an appendectomy so that the patient doesn't bleed excessively, doesn't go into shock, experience a high frequency of post-operative infections, etc. Perhaps our showcases are a sobering reminder to us of our own programmatic "retardation" in this country in regards to residential services--that we really only have partial models and have not really "put it all together" to date. I want the optimum in residential service alternatives for our retarded citizens. Yet, we continue to think--then provide--along the lines of minimal models for major residential challenges.

Where are we today? We seem to be embracing many trends and models which are groping toward the future. In a word, we are in a very difficult transitional stage. Fred Krause clearly illustrated that the money is still going to the major backbone of this country's ongoing posture towards its retarded citizens: the large--and not so large--public institutions. His illustrations clearly documented the continuing fifteen-to-one money ratio of institutional expenditures versus community-based systems. So the majority of dollar flow is still going the same way, and one could easily surmise that there are just not enough dollars for both of these alternatives. It should be pointed out that this ratio of dollars invested and number of individuals served in the local system will persist unless a concerted effort is made to serve retarded individuals in their home communities.

trends
and
models

Currently, we have "mixed" residential models, evolving administrative models and systems and rather clear legal guidelines. We still also have the partially met expectations of advocates. In this current transition I would remind you that during this Residential Forum there were primarily young people making the presentations. Great! We do not have to worry about the future when we have so many young people giving such high quality presentations--reflective of their deep and ongoing personal commitments to this field of endeavor. This area is going to be their career, their lives--and it will be their career fulfillment or personal nightmare, depending on how real they are, how concerned, how true to themselves. In brief, our retarded citizens are in good hands!

Trends and Roadblocks

> "Teach your children well and feed them on your dreams;
> the ones they picked, and the ones you will be known by.
> Don't ever ask them why; if they told you, you would cry."
>
> Crosby, Stills, Nash and Young

During a trip recently to Ireland my wife and I visited a residential facility for the retarded which had been hailed as the flagship of Ireland's program for its retarded citizens. Small, home-like, modern (and full day) programming, well staffed by friendly and obviously involved personnel--it was impressive. My wife suddenly asked, "Well, Frank, doesn't this fine facility make you really rethink your position on public institutions?" Good question! Yet, before I could answer her, we were literally surrounded by eight or nine friendly young residents who asked to have a picture taken, where we were from, etc. As we made the circle of introductions I noted that she asked how they liked living here and did they want to stay. Amazingly, each enjoyed the facility and yet each articulated a pressing wish to "Go home," "Be with mom," and "Work at home!" It was disconcerting to both of us and not in keeping with our predicted impressions of 15 minutes earlier. I was reminded of this experience when I noted the following story in the Chicago Tribune last Thanksgiving. It was entitled, **At 28, His Life Is Finally, and Joyfully, Put Together;**

> When we offer thanks today, I guess we're supposed to offer them to the Maker. Well, I know this guy He didn't make very well. And then He gave him a few more millstones, too. The guy's name is Joseph Kadlub, and it's a testimony to the strength of human will that he probably has more thanks to give this year than the rest of us. Joseph is 28 and mentally retarded--a term I hate. He is legally blind. Until recently he weighed close to 300 pounds. He is also, for all practical purposes, an orphan.
>
> When Joseph was a year old, he was treated at St. Vincent's Hospital for malnutrition and neglect. At 3 he was taken from his mother--whom he hasn't seen since--and placed in a succession of five foster homes in four years. At 7 he was committed, on a mental deficiency petition, to the Lincoln State School for the Mentally Retarded. He languished there for 16 years--until the day, in 1971, when he decided he wanted to get out and live like anyone else. That meant a paying job, a place of his own, and freedom of movement.
>
> But I prefer to let him tell it:
>
> "At Lincoln there was this big row of beds on one side, and a big row of beds on the other side. In the middle, people just played around. They had jobs at Lincoln, but they play dirty. You didn't get paid or nothing. And some sit down and do nothing while I do all the work. I had went on trips outside, and I felt like something, so--told people I wanted to leave, that I'm not sick. I'm not sick at all. I said I wanted to go to stores and all that stuff. I don't like to be closed in. I want to be someplace I can just go out."
>
> As you've noticed, Joseph has a speech problem. Those close to his case believe it's due in part to spending most of his life around people more retarded than he.
>
> It took time, but Joseph was finally sent to a private sheltered-care facility with the state paying the tab. But Joseph didn't like it there

either. "They keep the doors open and people steal. There were 200 people, and too many nurses. I said Lincoln State the same thing as here."

What he wanted was someone to teach him skills he sensed he needed to live on his own. The skills he wanted would hurt your heart: Cooking. Doing laundry. Riding the bus. Counting money. Paying bills. An immersion course in simple self-respect.

Three years ago, Joseph, living in yet another residential shelter, was placed in the vocational program of the Chicago School and Workshop for the Retarded. The School operates workshops for people with moderate mental handicaps. They work on assembly lines that simulate real working conditions, packaging goods and fitting parts together for private industry.

Joseph began to take off. His IQ rose from 49, when he was at Lincoln, to 57, then to 67. He has shed more than 40 pounds. He has become what his work supervisor, Rudy Herdeck, calls, "the best packer we've got"; the remark caused Joseph to shrug modestly and reply, "It's just my hands, they do the work."

A year ago, Joseph was accepted at Renaissance House, 2201 W. Devon Avenue, the residential facility of the Chicago School and Workshop. The goal of the Workshop is to place the School's hundreds of workers--many of whom will live in shelters or with their families the rest of their lives--in private day jobs. The goal of Renaissance House--which is more selective and has only 20 residents--is to teach living on one's own.

If you think Jimmy Carter has been born again, you ought to see Joseph. He has learned to cook, showing an excessive fondness for cheeseburgers. He has been taught how to care for an apartment. He has checking and savings accounts. Once a week he takes a money-management course, in which he learns how to save--from the 80 cents an hour he makes at the workshop and the $25.00 a month he gets from the state benefits that support him at Renaissance House. Because he now travels freely about town himself--and has discovered shopping--he has only $11 saved. But he's getting better at budgeting.

"He's frugal, he doesn't try to buy everything," Clair Hellstern, a public health nurse who has befriended him, said kindly. Joseph shook his head sadly. "Sometimes I do, sometimes I don't," he said.

Perhaps the most amazing thing about Joseph is his skiing. Since 1974 he has been a part of the Blind Outdoor Leisure Program and has been to Aspen and Snowmass four times. He skiis with poles attached to those of a guide behind him. A tug lets him know when to turn. Last year he went by himself: Took a cab to the airport, boarded the plane alone. He stayed with an Aspen ski instructor who has become his good and great friend. "I was scared, but I made it anyway. Went there and came back," Joseph said. "We were more nervous than he was," said Bill Applington, program director at Renaissance House.

Why do I write about all this at Thanksgiving? Because Joseph's about to get his wish.

Soon he'll graduate from the Levy Workshop, 6610 N. Clark St., to the Chicago School's placement center at Montrose and Ravenswood. He'll get intensive training while they find him a full-time outside job. He's also moving into the "training" apartment at Renaissance House, with a roommate, Eddie. They will live by themselves, away from the other group, to simulate independent living.

And sometime before next June, Joseph Kadlub will move to an apartment of his own--maybe even in Aspen. "Clean air, a small town, and nice mountains," Joseph noted.

His counselors talk a lot about his great motivation, his long concentration span, his will to make it.

But he might have lived out his life in the vegetable patch had he not grasped some simple truths.

"It makes me feel good to work, just to do something. It means I don't be lazy," he told me. "I'd like to grow up and see what's outside and have friends.

"I got my wish. It came out good. 'Cause I just don't like to be locked up and not do nothing."

self-concept

You will note that Joseph does not consider himself as "sick." It may be difficult for some individuals to fully realize that the Josephs of this world can say, "I'm OK. I'm intact. Despite your label, I'm a human being who wants freedom, the dignity of work and to have my hopes and dreams just the way you do." Later, in the article, he complained about being placed with people who were more retarded than he. Is he suggesting that we tend to encourage more signs and expectations of mental retardation? Sort of like prosthetic helps that do not help, but instead, tend to strangle developmental potentials. Or does it induce regression of behavior--as has been clearly documented in and out of the field of retardation (e.g., the work by Bowlby and Spitz on young children who are sent to live among strangers--away from their loved ones. These children tend to lose weight, become very withdrawn, autistic and some died). What skills did Joseph feel that he needed to learn to live out in the world? They were rather elementary and easy to provide: cooking, doing laundry, riding the bus, counting money, etc. An impossible dream? Does it really take elegant programming to provide Joseph with these adult self-help skills? I think not.

I want to stress that this story of Joseph clearly underscores that the personnel at his large institutional "home" did listen to him and shared--indeed they actively supported--his dreams. Otherwise, he never would have started on the road out of there. Let's not be critical of institutional personnel since they so often tend to be just as dehumanized as those they diligently try to serve in these grim settings.

sensitivity

You will note that Joseph's measured intelligence rose from 49 (while at the Lincoln facility) to 57, and then to 67. Why? Poor testing? Bias? I think not. Rather I would suggest to you that the global phenomenon termed human intelligence is only noted (i.e., truly tested) in that experimental interface between what life has brought the individual over the years and the current challenges of his environment. In other words, if there are no meaningful challenges there is precious little to measure and/or observe. I clearly learned this lesson in the early sixties during a research protocol on a muscle relaxant drug to lessen the muscle spasticity of motor impaired young retarded citizens. The study design and dosage schedule was clean cut and sound. Yet, a colleague noted, "Frank, if these youngsters are never permitted to stand in their cribs or attempts made to help them walk--how can you assess spasticity?" In other words, if the anti-gravity muscles are not called into action via the interface of experience (i.e., standing or walking)--there is no distinct spasticity elicited and the drug could not be adequately tested! The same phenomenon occurs with the attempts to assess intelligence in a child (or adult) who has not been placed in an optimal setting for challenging his problem solving or social adaptive abilities.

development
is
continuous

In brief, this news article makes a grand lie of the continuing litany that the severely retarded, multiply handicapped citizens "belong in the institutions because they represent the lost generation." Joseph is retarded, obese, has poor vision and comes from a troubled background. Yet he does not have to remain in that "large place out in the country," left to languish away with no one to attend to his pleas for help. This Residential Forum has shown other ways--beyond Joseph's sterling example--for these fellow citizens to have a more meaningful part in the promises of America.

Too often today, when we speak of residential services for the retarded, we focus unduly on children and the severely retarded. Yet, in my experience, the severely retarded can be more quickly and optimally served expectations

in generic services in the community--in contrast to the emotionally disturbed retarded citizen who frequently does need the structured setting of institutional services. After all, the young children are not going to the large public institutions in anywhere near the number that they did a scant decade ago. Yet, the major challenges, in my opinion, are the adult retarded citizens, like Joseph, who, because of the complexity of their handicaps are viewed as "severely" involved. It seems to me that they are the easiest to serve, especially in contrast to mildly and/or moderately retarded individuals who have associated behavioral problems. A major current-future challenge is to truly serve the severely handicapped Josephs of our country who have been permitted to languish in the institutions.

human rights

Who will listen to the Josephs in their muted cries for help? Clearly, the judges of our country have listened and acted. Note that the language of the judge in the Likins case in Minnesota does answer the cry for help that had been previously lost amongst the hollow echoes of state bureaucracy and misplaced priorities. Additionally, as Paul Friedman noted, the Bartley v. Kremens case, starting with the apparent adversary notion of rights of children versus rights of their parents, raises the question of who has the right in this world to send a child away to live his life among strangers. This lingering posture reminds one of the Swedish poet, Erik Lindegren's observation, "To believe you are born with bad luck though you were merely born."

mainstream

Community-based residential facilities must be designed to avoid the problems of dehumanization and neglect which have characterized the large institution. They should be small in size, homelike in atmosphere and located within the mainstream of the community. Simply providing the mentally retarded child or adult with a place to live is not enough to ensure that he will develop to his maximum potential. A full continuum of needed services must also be available in the community; services such as special education, vocational training, religious education, recreational services, etc.

costs

Comparative studies have shown that community placement is less costly than institutionalization (e.g., Atlanta Association for Retarded Citizens, 1972).[1] The work of Conley (1971[2] and 1973[3]) has presented detailed analyses of the fiscal disbenefits which the American economy must bear as a result of institutionalizing the mentally retarded. There is also a sizeable body of research demonstrating the benefits of community living which accrue to mentally retarded children and adults in terms of increased opportunities for learning, growth and development. Yet, despite the strong case for community-based residential programming, institutionalization remains the dominant form of residential care for retarded persons in America.

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[1] Atlanta Association for Retarded Citizens. A Study of Georgia's Services for the Mentally Retarded. Atlanta, Georgia: AARC, 1972.

A recent beautiful book from England on retardation focused on the personal vicissitudes commonly experienced in institutions for the retarded; it was succinctly entitled, *Put Away*. Can someone put a human being "away" in this world? I think not. Not without due process. Clearly the following recent events have significantly altered this dehumanizing posture: the Partlow case, the *Likins* case, the *Bartley v. Kremens* case, the ICF/MR regulations (if the Federal Government has the courage to truly demand their firm implementation by March of 1977 instead of waffling first in Oklahoma and then the rest of the country), all hold great promise for a significant constricture on the construction or operation of the human warehouses. Another significant event has been mandatory education (a tip of our hat to the parents of the retarded in Pennsylvania!) which underscored the right to education for all retarded citizens. A recent article in the education section of *Time* magazine listed the right to education as next only to the civil rights movement of the fifties as having the greatest impact on providing services to the people of this country. The demand for generic educational services for our retarded citizens, backed by hard dollars, clearly reflects the revolution of the general public's thinking about who can be helped and how our society is going to get it done.

due process

Take these benchmark legal cases, the facility-program regulations and mandatory education, add to them the fact that no major group of individuals is really pleased with our current large public institutions, and we must ask: What do we do next to break the lockstep of the large public institutions which still persist as America's residential "answer" for many of its citizens--replete with the 15-to-1 dollar inconsistency?

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[2] Conley, R. W. An assessment of the economic and non-economic costs and benefits of mental retardation programs. In: Julius S. Cohen, et al (eds.) *Benefit-Cost Analysis for Mental Retardation Programs: Theoretical Considerations and a Model for Application*. Ann Arbor, Michigan: The University of Michigan, Publications Distribution Service, 1971.

[3] Conley, R. W. *The Economics of Mental Retardation*. Baltimore, Maryland: Johns Hopkins University Press, 1973.

I am tempted to stop here, be friendly and say, "Come back next year and we'll talk about the moral dimensions of our current residential quandry." Rather, I will now speak (for the remainder of this presentation) as Frank Menolascino, not as a senior officer of the National Association for Retarded Citizens, and directly share with you what I see as the major future trends in providing residential services for our retarded citizens.

need for change

The time has come for us to clearly say that the system of state supported, large public institutions as the mainstay of our country's primary residential alternative for its retarded citizens has failed them on a grand scale. We have to also look closely at the Showcases displayed in this Forum and ask, "What are their relationships to the developmental implications of future residential services for retarded citizens?" Looking at the mountain of data we now have, I think we must say to ourselves that there has got to be another way to spur change in the seventies--lest we talk only to each other and become convinced that the issues will "take care of themselves over time." For example, in the closing section of Changing Patterns of Residential Services, a President's Committee publication in 1969, Gunnar Dywad wrote a timeless contribution. He noted the continuing inertia to specific changes even though the ideology and associated technology needed for change were readily available! Gunnar spoke of the roadblocks to changes in residential services and the roadblocks were variants of the same posture of professionals and bureaucrats who had led the retarded into the wilderness during the first two decades of this century. They had spoken of mass sterilization, forced labor and low budget institutions as "good enough" for the retarded citizens of our country. Gunnar noted that the models for major changes were available in 1969 and his comments are as timely today as they were eight years ago.

human services

Lest the professionals feel that I am unduly picking on them, I want to note that this is a posture of many other human service components. A clear example of this continuing professional posture appeared in a recent issue of Business Week. The article discussed the negative income tax (i.e., family maintenance programs) which could "...as most economists see it, be the answer to the welfare mess by replacing many of the individual programs with a universal federally financed negative income tax." The article notes that this posture has been frequently discussed, kicked around and typically was a highly recommended course of action. During the last five years there have been five large-scale, scientifically designed programs to assess what does happen when you actually provide a family maintenance program. In the past, the article noted, people thought that if you had this program folks wouldn't work, welfare recipients would spawn another generation of the same, education levels would flatten out because there would be no positive modeling for children, etc. The article points out that just the opposite results have been reported in the five recently completed national studies. Why do I bring this to your attention? Issues in retardation encompass some of the same issues as in the area of family subsidy. Further, they are both researchable issues, and rather than your philosophy or mine, or your prejudice versus mine, we now have the technology to dissect out what works and what does not. As to the professional and bureaucratic "roadblocks" which ride the backs of those they are supposed to serve, the following comment from this article is directly appropriate. "Not withstanding the broad support among experts, Congress has been slow to embrace the negative income tax idea. One reason has been the pressure from welfare bureaucrats and special interest groups that have a stake in maintaining programs that a negative income tax might supplant." This suggests that paid public employees have kingdoms and an obsession with territoriality. Even when you have hard data, bureaucrats and special interest groups do not want to give up the hydra-headed welfare bureaucracy (or the institutional bureaucracy). I would commend to your attention that this same professional posture has stymied the potential dynamic of movement towards the currently available, wide spectrum of community-based residential programs (as clearly shown during this Residential Forum) and, in my opinion, has been a gross disservice to those citizens we are all privileged to serve: our mentally retarded fellow citizens!

bureaucracies

Stumbling over the Better on the Way to the Best

> "Am I mad that I should cherish that which bears but bitter fruit?
> I will tear it from my bosom, though my heart be at its roots."
>
> Tennyson

As I thought about the events of this Residential Forum I reflected on the above-noted admonition from Lord Tennyson. To appreciably alter our current posture toward residential services I believe we will have to literally replace the sources of the bitter fruit--though they may be deeply embedded in the hearts and brains of individuals whose current systems of services are not very helpful to our retarded citizens. Let them take care of their own personal identity problems and allied bureaucratic needs--without remaining as the roadblocks which continue the wide scale dehumanizing of retarded individuals.

Truly we are in a transitional period, from the old residential model of a remote abode for the "helpless and hopeless" to the wide variety of complementarity

currently enhancing models which hold the promise of bringing about meaningful change. As I reflected on the diversity of views in our current transitional period I thought of the principle of complementarity from the field of nuclear physics. Nils Bohr received the Nobel Prize because, in the second decade of this century, he closely studied the three then current theories about the nature of light and noted that each was correct as far as it went. He took from each of these incomplete ideas their principle components and found that when he combined these components they were complementary and together explained the nature of light. That is the principle of complementarity from the world of atomic physics.

transition

In our Showcases there is the potential to apply the same principle of complementarity. We can abstract, in the current dynamic movements towards rights, new human service systems, new technology and the Association for Retarded Citizens' movement of continuing advocacy--we do have the ideas which, when put together via the complementarity principle, can give us the direly needed new horizons in residential services. We are in transition, yes, and I would suggest that we seriously consider--lest we repeat the sins of the past--a national moratorium on all major residential plans; go back to our respective states and, as John McGee clearly noted, seriously reflect on how we can clearly advocate for the full rights of the mentally retarded citizens of America. Following this moratorium (i.e., for the rest of 1977) we could then say, "This is the national posture we want--a full system of residential services in conjunction with the educational-vocational-social-recreational services needed--operating where our families reside." Yes, we could decide without the roadblocks of the myth of limited financial resources, the conflicting needs of politicians or the outmoded professional assumptions about limited developmental potentials of retarded persons. We would have to truly look at ourselves and then fully live up to our past and present promises such as adherence to the NARC policy statements on residential services. It is basically a problem of true advocacy, and we of the ARC movement must literally drag the field forward. In this transitional period we will fully support the family and stop the continuing pathways to patienthood into the large or not-so-large "modern" colonies for the retarded. As we have noted in this Residential Forum, the evolving transitional models are there. We will have reaffirmed that there will no longer be any "lost generations" in this country--of whatever "labels"--and reaffirmed that no American is expendable.

Lest I seem "completely unrealistic" may I suggest that this moratorium will clear the air of the halfway solutions over which we continue to stumble in our country. We will no longer need to talk of what to do with normalization

the "givens" from our grim past; we can embrace our collective consciences and "go all the way." Yet, what is that "way?" First, the principle of normalization and the developmental approach to the growth of our retarded citizens--of whatever age, type or level of handicap--really have no serious detractors, theoretically or practically, as a firm basis for residential programs. So let's cease the specious arguments across our country such as the statement, "Normalization is a bunch of junk and is only supported by a lot of enthusiasm." Show me a better posture towards our retarded citizens--show me one! Secondly we will fully support funding for the family as the primary unit of care and purchaser of services--via full funding for generic services in the community and say to heck with the maddening array of funding sources which Rita Charron noted! The overriding role of our ARC movement, as John McGee mentioned and as Ms. Burda also underscored in her presentation at Indianapolis, will then be to closely monitor this family-based utilization of generic services. We can, and must, pull together all of our resources; public awareness, all kinds of advocacy, ongoing aggressive Governmental Affairs efforts, etc. We can leap-frog the current transitional scene, beyond the ENCOR and Macomb-Oakland models and beyond the Scandinavian models of the recent past.

We must directly face the bitter fact that we are currently serving our retarded citizens in the residential models of the sixties era. Yet, it is reassuring to me to note that in the seventies the Scandinavians are coming to America on the Dybwad Awards! In the sixties we went there and we saw the ultimate in modern small scale institutions--in contrast to what they, in turn, viewed our institutions as: being not so clean "cattle barns." In the seventies the Scandinavians are coming to America, and what do they see? Partial models? Mixed blessings? Or, in the latter part of this decade, will they see the best which our great country has to offer for its retarded citizens?

Moral Imperatives to Action

"Will the veiled sister pray for
Those who walk in darkness,
Those who are torn on the horn between
    season and season, time and
    time, between power and power,
    those who wait
In darkness? Will the veiled sister pray
For children at the gate
Who will not go away and cannot pray?"

T.S. Eliot

dichotomies

Increasingly, when I attend such events as this Residential Forum, I abstract them into antitheses. On the one hand, the dream, the promise, the idealism, the hard and clean moral decision of the individual whose conscience demands that he or she use his or her knowledge to improve the lot of retarded citizens as much as he or she knows how. On the other hand, the status quo, the frozen negative attitudes and, increasingly today, the slick Madison Avenue packaging of the same old dreary institutional story. There was a time perhaps when this dichotomy between morality and indifference was not so sharp. The earliest institutions for mentally retarded persons in this country were, in fact, superb training schools and those who entered returned to society better trained and more fully developed individuals. That day certainly is past. Today institutions for the retarded are too often a one-way street to squalor and oblivion. Not all institutions compare with the abomination of the infamous Willowbrook in New York, but I can recommend few of the many I have visited as humane places where a retarded person can fully develop as a growing, learning individual. Institutions for the retarded per se are overcrowded, understaffed, dehumanizing and incapable of delivering a fraction of the opportunity and enrichment of normal society.

But these are retarded people, says the institutional superintendent. This is where society sends them. We are understaffed and overworked. But we do the best we can, he adds.

awareness

It is not, I would contend, that such individuals are immoral--they are simply immune to the demands of morality. Institutional blinders are indeed restrictive, and in time the rock-bottom dehumanizing minimum of custodial care begins to look like "the best we can do." A shocked public may demand entrance to view this affront to our ideas, but the fortress walls are up; visitors' passes are necessary; no cameras, thank you. At this point an appeal to the morality of the institution keepers, to their ideals and their professional ethos is so often seen by them as irrelevant. The effect of the institution is to make them as blind to the needs and human potentials of the retarded individual as the fearful parents who first placed their child within its walls.

alternatives

Is there an alternative? This ubiquitous question is testimony to our own blindness to the capabilities of the mentally retarded. The alternative, of course, is outside the institution--in the society of home and community that nourishes us, challenges us, forces us to grow and fulfills us. Every member of our society has varying educational, counseling, medical and vocational needs--why not meet the similar needs of the retarded in the same fashion, in their communities? The success of community-based services for the retarded is persuasive proof of the capabilities of retarded persons; these programs are also a validation of a moral attitude that perceives an ideal and strives to make it real. Those who dismiss the promise of community service programs as "phony public relations gimmicks" and "distortions" are guilty of a double blindness: an inability to see not only what is but what should be. It is not culturally normal for one to spend his life in an institution, much less in a warehouse that calls itself a therapeutic center. It is, in fact, horrendous that anyone does. Cultural norms cannot be learned in an abnormal milieu. This is a truism today, and if the bureaucrats and professionals of 25 years ago could plead ignorance of an alternative to warehousing as an excuse, no such plea is possible today. The pioneering efforts of Itard, Seguin and Howe proved that retarded persons could learn; the mountain of data compiled since then has proven how much they could learn. These are inconvenient facts for the defenders of large public institutions, and one can only conclude that by denying these realities, this data, these facts, they are confirming their own roadblocks to becoming truly contributing helpers of retarded citizens. Excellent models of community service programs exist and their value and workability is rapidly being proven. The knowledge on which these service systems are based is readily accessible to those who recognize that a life based on the cultural norms of home, work and community is not only a possibility for retarded persons but, I believe, a moral necessity.

cultural norms

Finally, there is knowledge itself and the moral demands it creates. The social-educational-vocational services have been traditionally viewed as helping professionals and, unless the practitioners are morally bankrupt, they **must** use what is known to help our retarded citizens attain cultural norms as far as is possible.

knowledge

To work in community-based services for the retarded is not a total divorce from the "system." The radical posture may be tempting, but ultimately it is isolating and self-defeating. I would advise against it. In my experience, the system that fosters and supports the public institutions can be persuaded to support the community-based alternatives to it. In fact, if one is serious about change, the system must be dealt with and persuaded--for its components are parents, professionals, legislators and institutional personnel whose support is necessary in order to initiate a true alternative to institutional care. The community-based system, once established, then depends upon the institution to refer clients back into the community and may find that former institutional personnel are early and valuable applicants for work in the alternative system. Thus, while an arm-in-arm or hand-in-hand relationship with the institution may be uncomfortable, communication between the two systems is vital.

alternative system

The dichotomy of the two systems is an unnatural one, and the political competition between them can be a distraction from, and detriment to, the proper goal of serving retarded persons. There is evidence, however, role of the institution

that systems of care that utilize both institutional and community resources are evolving. As the 1976 Report of the President's Committee on Mental Retardation noted, there appears to be a major reorientation of the role of the public institutions. The Report points to three models of services all of which differ significantly from the traditional model of the isolated institution. The first of these is the urban residential center which provides services to residents and day services to retarded citizens who live in the community. An example of the second model is the effort to convert institutions into specialty residential facilities which prepare clients for community living where they are served by community-based programs. The third model is the regional service delivery system in which the institution is a central resource connected by communication, outreach activities and the flow of clients to the community-based components of the system. One should note that these are fluid, not final, models; but they are extremely hopeful signs that institutions and community-based services can work together to provide normalizing services for our retarded citizens.

The question of public-political-professional accomplishments and its allied issue of morality, then, is not "us" against "them" or community-based residential programs versus institutions. It is more a matter of the individual service provider's perception of what we all, as human beings, deserve and his assessment of his knowledge, power and vision to effect the necessary changes. I would stress that service providers must focus on the need for individual programming for each and every retarded citizen, regardless of where they reside. If that attitude were common to professionals in mental retardation, the results would vary, for morality leads people in many directions. I do not doubt, however, that the futures of retarded persons would be a hundredfold brighter; that there would be many shapes and forms of residential service models; and that more young and dedicated advocates and professionals would join, anxious to use their knowledge, skill and enthusiasm in service to persons so long denied the normal life experiences we take for granted.

The legal rights of mentally retarded persons are, at present, being affirmed in the courts. What is crucial now is the affirmation of their human rights by society; the recognition of them as learning, growing persons who deserve the opportunities for self-fulfillment as much as you and I. From my own experience with community-based programs in Nebraska, I can say that, when the advocates and professionals can embrace this ideal as the proper moral expression of their involvement and full utilization of their knowledge, the acceptance of mentally retarded persons by our society will not be far behind.

Conclusion

consistent goals

I believe that we must rethink, reflect and then actually seek to finalize a timetable to phase down all of the large public institutions for the retarded in our country. A ten-year period should be long enough to incrementally make the transition from where we are to where we must be: within the family, in the home and in the community. I am fully aware that we have a long way to go, and again I speak as one person whose crystal ball, God knows, is cloudy. I have no periscope on the future, but after 18 years in this field of service I remain deeply bothered by hearing the children in the wilderness singing, as Fred Krause mentioned. The President's Committee on Mental Retardation, in its MR 2000 Report, predicted that by the end of this century the current institutions will be drastically altered. Federal goals talk about a reduction of a third or a quarter of the current population of institutionalized retarded citizens. What is sinful about going all the way during the next ten years? Where is the roadblock to a movement which had the courage to lift the initial horizons of help and hope--in the early fifties--to go the next big step of serving all our retarded citizens as co-equal citizens who truly deserve full opportunities to share in the promises of America? I spoke this way at a national conference just one week ago and someone said to me, "You know, Frank, you sound as 'old fashioned' as our new president. He speaks of compassion, and you speak of bringing equal opportunity to the retarded for wholesome and responsive residential environments." The obtainment of wholesome social-adaptive benefits from responsive environments and how they can be individualized to meet the needs of all retarded citizens--regardless of the nature of their handicaps--is how Elizabeth Boggs recently reinterpreted the principle of normalization. She wanted for her David a truly responsive environment. Yes, we must talk the same way about **all** of the programs--current and future--for every retarded child and adult in this country. Not because he's obese, or has an IQ of 45, is blind or microcephalic, has spasticity in one leg--you fill in the blanks--but because he's a human being who is a fellow citizen. Let us reutilize the traditional truths of the early humanism our country displayed toward its retarded citizens and turn our back on the roadblocks--consciously, with purpose and fully commit ourselves to provide truly responsive models of residential services to enhance the lives of our retarded citizens.

responsive service models

We talk too much about our movement's fears and roadblocks to capturing the dream of full personal fulfillment for our retarded citizens. Dissention within our movement, unions, conflicting advocacy postures, the negative fallout of politics, etc. We talk too much in terms of being fearful of doing what we have known for a long time **must** be done to give retarded persons a meaningful place to live and grow as full citizens in their country.

fears

advocacy

I am aware that this major push for full advocacy will demand a realignment of our, at times, "too nice" posture towards state-local planners and service delivery personnel. We must no longer accept just talking to them at the times of crisis--and then they make the real dollar decisions in the back room. The current era of openness in government will aid us greatly. Have you noticed how many public officials and employees always seem friendly until it comes to unfavorable publicity or unpopular policy decisions? Then we, the advocates, become typically viewed as incoherent, incompetent, troublesome, etc. Since our movement has been the major impetus for program changes and a central stimulus for the rapidly increasing flow of dollars to programs, we can demand that we stop being viewed as just good front people who "...just can't understand the buck." We must demand coherent state plans--replete with the dollars discussed openly and up front. Many who currently utilize the institutions are very hesitant about the thrust and eventual goals of deinstitutionalization. Yes, this posture was badly battered by the mental health people who rapidly closed down and injudiciously dumped people into boarding houses, nursing homes or literally out in the streets. This trend in mental health was very disrespectful of parents, their sons and daughters. In contrast, and as I said earlier, the thousands of employees in the institutions for the retarded have been and are good and diligent helpers to our retarded citizens. We must not repeat the mental health scene, and the moratorium which I am suggesting must take a hard look at step-by-step planning and implementation components which directly reflect on the personal rights of all parties involved.

future potentials

As many have noted, there is in this country a great untapped opportunity to fully utilize the mountain of available knowledge about modern residential alternatives. Yet, I keep hearing, in state after state, "Yes, but ..." and I have listened very carefully to what the "buts" are. Ten years ago they referred to not having enough trained people; today that stricture is no longer a valid one. That was one of the reasons why our early institutions failed at the turn of this century--because we had a rural-based population and insufficient numbers of trained people to serve the retarded where their families resided. Today we have a rapidly increasing army of trained personnel and, thank God, they are young people without the professional blindspots of the past. Another frequent "but" is money. Bluntly, I have never believed that our country, which has a one trillion dollar Gross National Product, cannot do anything it wants to do! We can put a man on the moon, fight an unpopular war or we can dehumanize people. Surely we can demand that the investment in responsive residential alternatives for our retarded citizens is a noble and high priority item for investing in the current-future potentials of all of our citizens!

I clearly note a changing posture at the federal level towards human services and an openness which is matched with a concern for all of our citizens. Let's capture this changing posture and continue to change the horizons of hope and help for our retarded citizens in the area of residential services. It cries out to be accomplished by us, the major organized movement of active advocates for the retarded citizens of our country. A significant challenge, yes, but one which is in keeping with our movement's ongoing work, our shared love and our ongoing commitment to what must be done for, and with, the retarded citizens of America.

Community Based Residential Services:

a Bibliography

national association
for retarded citizens

NARC Research and Demonstration Institute

2709 Avenue E East • P.O. Box 6109 • Arlington, Texas 76011 • (817) 261-4961

Adult Group Home Procedure Manual. 1974. North Carolina Department of Human Resources, 325 N. Salisbury Street, Raleigh, North Carolina 27611. Cost: $3.75.

An Apartment Living Plan to Promote Integration and Normalization of Mentally Retarded Adults. 1971, by Margaret Fritz, Wolf Wolfensberger and Mel Knowlton. National Institute on Mental Retardation, Kinsmen Building, York University, 4700 Keele Street, Downsview (Toronto) Ontario, Canada M3J1P3. Cost: $1.50.

Analyzing Costs in a Residential Facility for Children: A Step-by-Step Manual. 1969. Child Welfare League of America, 67 Irving Place, New York, New York 10003. Cost: $3.00.

Designed to meet the need for a workable, uniform method of measuring or analyzing costs in a children's residential group care facility, the system is planned for self-administration and needs no special forms. Outlining a method for breaking down the costs of operating an institution under voluntary or government auspices, or an institution service provided by a voluntary multi-service agency, the manual is organized in five major sections. These are: (1) Organizing for costs analysis - staff assignments are made and decisions are reached on handling problems; (2) Expenses in the agency's books are analyzed and allocated; (3) Parent organization expenses are applied to institution service; (4) Donated goods and services - imputed costs - the difference between the commercial value and the actual expense to the agency of donations are identified; and (5) Preparing cost analysis report - based on the above information, a cost analysis report is prepared, consisting of four or five exhibits supported by a written year-end interpretation. Developed by a U.S. Children's Bureau financed project in the American University School of Government and Public Administration.

As Close as Possible: A Study of Community Residences for Retarded Adults. 1974, by Bruce Baker, Gary B. Seltzer and Marsha M. Seltzer. Read House, Harvard University, Cambridge, Massachusetts 02138. Cost: $12.50.

The PARC Project (Planning Alternatives for Retarded Citizens) was undertaken to explore the many ways in which retarded adults are beginning to live in communities. This is a descriptive study of alternative models of residential living for retarded adults and a survey of community residences across the nation which also included an on-site examination of 15 programs. Chapter 1 develops background themes, followed by a description of procedures and an overview of the survey results from 381 programs and issues raised by them. Chapters 4-13 consider in more depth alternative models currently serving retarded adults. Various issues are highlighted in chapters 14-15, and recommendations are made relevant to Massachusetts. Appendices include a related paper on behavior modification in a group home.

Benefit-Cost Analysis for Mental Retardation Programs: Theoretical Considerations and a Model for Application. 1971, edited by Julius S. Cohen, et al. Publications Distribution Service, University of Michigan, 615 E. University, Ann Arbor, Michigan 48106. Cost: $1.25.

Final report on the project "Cost Benefit/Cost Effectiveness Analysis of Educational Programs," at the Institute for the Study of Mental Retardation and Related Disabilities.

A Common Sense Approach to Community Living Arrangements for the Mentally Retarded. 1975, by John W. Fanning. Charles C. Thomas Publishers, 301-327 E. Lawrence, Springfield, Illinois 62701. Cost: $8.50.

Ideas presented deal with the necessity for procurement of various types of insurance; checking zoning, fire and safety codes; how to deal with city ordinances; methods of selecting and securing household furnishings; ideas on designing individual training programs; use of community volunteers; transportation alternatives. There is a discussion of advantages and disadvantages of using couples as houseparents as opposed to single managers; steps in implementing training hostels, group homes, apartments, etc.; how to select a house and methods for screening residents. The book also includes discussions on the need for sex education for residents; a sample program evaluation scale; plus warnings of common pitfalls and problems in the planning and setting up of community living arrangements.

Community Group Homes for the Mentally Retarded: Utilization of Evaluation Results for Program Planning and Quality Control. 1974, by Angela Yaron and James Graves. State of Colorado, Department of Institutions, Division of Mental Retardation, 306 State Services Building, Denver, Colorado 80203. Cost: Unknown.

This report presents a working model of project evaluation, the purposes of which are: (a) to help staff improve the quality of their service through ongoing monitoring of program and client; and (b) provide adequate accountability regarding the effectiveness of the program to the state. Designed to monitor and evaluate a three-year project called "Colorado's New Patterns of Living for the Mentally Retarded" (which involves the establishment of small, community-based group homes for retarded individuals), the discussion focuses on monitoring client and program movement, assessment of program objectives, degree of achievement, emerging patterns and utilization of evaluation results for program planning and quality control.

Community Homes for the Retarded. 1975, by Joel S. Bergman (editor). Lexington, Massachusetts. D. C. Heath and Company. Cost: $11.00.

This publication discusses the planning and implementation of a group home, illustrating community involvement, selection and training of house managers, program guidelines and budget considerations.

Community Placement of the Mentally Retarded: A Handbook for Community Agencies and Social Work Practitioners. 1973, by Richard A Mamula and Nate Newman. Charles C. Thomas Publishers, 301-327 E. Lawrence, Springfield, Illinois 62703. Cost: $6.95.

The stated intent of the authors is to create a handbook for social work practitioners in the field of community placement which (a) seriously examines the basic components of the community placement concept; (b) discusses its historical development; and (c) offers suggestions and a practical guideline for the development of effective community placement programs designed to meet the particular requirements of the individual communities and agencies involved.

Community Placement Program: An Examination of Process and Outcomes of Community Placement of Adults and Children From Mental Health Institutions in Michigan. 1974. Part I - Report. Part II - Technical Appendix. By the Michigan State Office of Health and Medical Affairs, Lansing, Michigan 48913. Cost: Unknown

A Community Respite Care Program for the Mentally Retarded and/or Physically Handicapped. 1976. A handbook by Deanna Shoob (36 pages). Childcare Assistance Program for Special Children, Inc., P.O. Box 1217, Springfield, Virginia 22151. Cost: $4.00.

A step-by-step discussion of how the Childcare Assistance Program developed its respite services is presented. The handbook includes staffing requirements, setting fees, methods of funding, recruitment and training of service providers.

A Comprehensive Manual on the Establishment and Operation of Community Residences for Developmentally Disabled Persons. 1975, by the Northern Virginia Association for Retarded Citizens, 105 E. Annandale Road, Suite 200A, Falls Church, Virginia 22046. Cost: $2.00 Softcover, $5.00 Looseleaf Binder.

This manual was compiled by the Northern Virginia Association for Retarded Citizens' staff in consultation with other public and private agencies. It represents two years' research in the area of community efforts to (1) prevent institutionalization and (2) aid persons in relocating out of institutions and into the community. Items covered in the manual include finance, zoning, home management, insurance and liability.

Creating the Community Alternative: Options and Innovations. Proceedings of a Conference, March 19-20, 1974. Hershey, Pennsylvania, 1974, by Horizon House Institute for Research and Development, 1019 Stafford House, 5555 Wissahickon Avenue, Philadelphia, Pennsylvania 19144. Cost: Unknown.

Specifically, the conference was designed to provide Pennsylvania mental health and mental retardation planners, administrators, service providers, public officials and interested citizens with new concepts relating to community alternatives. The program content of the conference was organized around three major sessions, each addressing a separate aspect of the conference theme: (1) Creating Alternatives for Optimum Residential Care; (2) Creating Alternatives to Promote Positive Adjustment in the Community; and (3) Creating Alternatives for Improved Case Management and Continuity of Care.

Creating a Foster Parent-Agency Handbook. By Helen D. Stone and Jeanne M. Hunzeker. Publication Service, Child Welfare League, 67 Irving Place, New York, New York 10003. Cost: $2.50.

This guide offers a uniform approach to the preparation of informational manuals and agreements between child care agencies and foster parents. Its purpose is to provide comprehensive subject material that can be adapted to the policies in each locality where agencies and foster families work together.

Deinstitutionalization: An Analytical Review and Sociological Perspective. National Institute of Mental Health, Series D, No. 4, 1976, by Leona L. Bachrach. Stock No. 017-024-00530-4. U.S. Government Printing Office, Washington, D.C. 20402. Cost: $1.10.

This study is primarily focused on mental hospitals and describes the issues of deinstitutionalization, examining them with the assistance of a theoretical framework. The framework used is functional in nature. "A fundamental and underlying assumption of the study is that many of the problems connected with deinstitutionalization are closely related to a general failure, first, to understand and/or pay adequate attention to the unique position of the mental hospital in American culture, and second, to make sufficient allowances for this uniqueness in the process of planning for social change."

Education for Foster Family Care: Model and Method for Foster Parents and Social Workers. 1974, by Helen D. Stone and Jeanne M. Hunzeker. Child Welfare League, 67 Irving Place, New York, New York 10003. Cost: $6.95.

The authors present basic material on preservice and inservice educational programming for foster parents and foster family social workers, together with a number of models of how these basics can be, and are being, implemented locally.

Establishing Community Based Homes for Developmentally Disabled Adults. By Dorothy Philbrick. Life Skills, Inc., 3803 East Lake Way, Redwood City, California 94062. Cost: $2.50.

The author, writing from her own experiences of establishing a small group home for developmentally disabled adults in California, provides practical advice appropriate for any geographical area. Ms. Philbrick believes that a small group home situated in the community where trained staff would teach each individual the necessary living skills, would furnish the incentive necessary for progress and the training that developmentally disabled adults should have to live a happy and fulfilled life.

An Evaluation of the Effects of Group Home Living. 1975, by Charles J. Seevers. Aux Chandelles, Elkhart County, P.O. Box 398, Bristol, Indiana 46507. Cost: Unknown.

Family Care Training Homes: Manual of Procedures. 1974, by Macomb-Oakland Regional Center, 16200 Nineteen Mile Road, Mt. Clemens, Michigan 48043. Cost: Unknown.

The Family Care Training Home Program of the Macomb-Oakland Regional Center in Michigan, a modification of the Family Care Program of the Michigan Department of Mental Health, consists of placing one to three mentally retarded individuals in a carefully selected private home in which the resident can live as a family member and receive both care and training. Not meant to be a life-long residence, it is a goal of this program that an individual maximize his potential and move into a more independent placement. Included are guidelines, procedures, descriptive material and forms (policy letters, checklists, evaluations, etc.), inservice training schedules and inservice training objectives for family care training homes.

Five Models of Foster Family Group Homes: A Systematic View of Foster Care. 1974, by Elizabeth A. Lawder, Roberta G. Andrews and Jon R. Andrews. Child Welfare League of America, 67 Irving Place, New York, New York 10003. Cost: $3.00.

The purpose of this monograph is to develop the concept of differentiated foster family care designed to serve a range of children and to describe several foster family models useful in putting this concept into practice. Illustrating the flexibility that an agency must have if it is to selectively adapt available resources to children, this publication sets forth one approach to developing a wider choice of family environments for the placed child.

Gaining Community Acceptance: A Handbook for Community Residence Planners. August, 1976. Patricia Stickney (ed.) Community Residences Information Services Program (CRISP) of the Westchester Community Services Council, 713 County Office Building, White Plains, New York 10601. Cost: $3.50.

The handbook is designed to provide residence planners with practical ideas and methods for analyzing a community and for determining strategies which can be effective in gaining support for a community residence and in resolving conflict; an examination of the obstacles caused by restrictive zoning codes, etc.; and a review of the role of the media in gaining support for community residences.

Group Homes for the Mentally Retarded. 1973 (Research and Training Center in Mental Retardation Monograph No. 1), edited by Carol K. Sigelman. Texas Tech University, Lubbock, Texas 79409. Cost: Unknown.

Growing out of a conference "Extended Living for the Mentally Retarded," held November 12-15, 1971, at Texas Tech University, this monograph presents papers reflecting a variety of viewpoints and perspectives on the development of group homes. Included are: An overview of the programs of the State of Washington along with sample guidelines for group homes in that state; regionalized network of community-based services for the retarded in Connecticut and the genesis of their group home programs (included also are several critical issues in planning and operating group homes ; a third describes three facilities for employable residents and discusses key management considerations in the development of sheltered living programs at the State School in Lubbock, Texas.

Group Homes: One Alternative. 1974, by Robert Goodfellow. Human Policy Press, P.O. Box 127, University Station, Syracuse, New York 13210. Cost: Unknown.

Written as a part of the series "Notes from the Center" from the Center on Human Policy at Syracuse University, an organization interested in studying and promoting services and life patterns which are as normal and non-stigmatizing as possible, this publication provides information on alternatives to institutional living, an issue and concern consistent with the Center's interests. Budget sample and sample outline for a group home proposal are included. ("Notes from the Center No. 7")

Guide to the Community. Vols. I, II, III. Elwyn Education Materials Center, Elwyn, Pennsylvania 19063. Cost: $2.95 each; Complete set $8.50.

Volume I - Employment, Money Management, Banking, Your Paycheck.
Volume II - Income Tax, Life Insurance, Health Insurance, Social Security.
Volume III - Driving a Car, Finding a Place to Live, Legal Emergencies, Community Services, Medical Emergencies. 1967. Rev. 1974.

Guidelines for the Establishment of a Community Group Home. 1973. Edited by Suzanne Turner, Ohio Developmental Disabilities, Inc., Suite 212, 2238 S. Hamilton, Columbus, Ohio 43227. (Note: Also available is Community Living for Ohio's Developmentally Disabled Citizens, 1974). Cost: Unknown.

Guidelines for Family Care Home Operators. 1972, by Paul J. Schrader and Rosyln R. Elms. Springer Publishing Co., 200 Park Avenue South, New York, New York 10003. Cost: $4.25.

How to Choose a Nursing Home: A Shopping and Rating Guide. 1974. Citizens for Better Care, 960 E. Jefferson Avenue, Detroit, Michigan 48207. Cost: Unknown.

Citizens for Better Care, a consumer action organization of persons and groups concerned with the improvement of nursing homes, homes for the aged and other facilities and the Institute for Gerontology of the University of Michigan/Wayne State University have prepared a checklist on aspects of nursing homes that are most important to the resident. Chiefly directed towards the older person who may be considering entering such a facility.

Independent Living Teaching Manual. 1975, by Robert L. Schalock. Mid-Nebraska Mental Retardation Services, P.O. Box 1146, Hastings, Nebraska 68901. Cost: $17.00 for set of 2 volumes.

The two-volume set includes an Independent Living Screening test manual in addition to this teaching manual. The manual contains a sequenced list of target behaviors, which, when remediated, combine to produce functional behaviors. Specific teaching objectives, materials and teaching techniques are also presented in reference to each target behavior.

The Mid-Nebraska program has also developed screening tests and teaching manuals for Basic Skills and for Competitive Employment.

Let Our Children Go: An Organizing Manual for Advocates and Parents. 1974, by Douglas Biklen. Human Policy Press, P.O. Box 127, University Station, Syracuse, New York. Cost: $3.50.

Designed for parents of children with disabilities, this publication summarizes the thoughts of parents and advocates who have struggled for resources to meet the needs of handicapped children. The role of advocacy is emphasized to ensure that the rights of handicapped people are upheld.

Long-Term Institutional Care and Alternative Solutions. Part I - 1972. Current Activities. American University Report - Vol. 1, by Frank Atelsek, et al. American University Development Education and Training Research Institute, Washington, D.C. U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Service, Medical Services Administration, Room 4609 HEWS, 330 C Street, S.W., Washington, D.C. 20201 (SRS-73-24508). Cost: Unknown.

Divided into two parts, the introductory chapter of Part I discusses some of the problems associated with the development of alternatives to institutional care. Also reported are current health care efforts which may prove relevant to future developments of non-institutional models of long-term care. Included are abstracts of recent program activities among federal agencies, an inventory of recent and ongoing research and demonstration projects and summary descriptions of how other countries provide long-term care. The three chapters of Part II discuss proposals for long-term care alternatives.

New Neighbors in Search of a Home. 1974, by Carolyn Cherington and Gunnar Dybwad (eds.) U.S. Government Printing Office, Superintendent of Documents, Washington, D.C. 20201. (DHEW Pub. No. (OHD)74-21004). Cost: $2.10.

Discussing philosophical and practical aspects of the retarded citizen's need for a home in the community, this document offers guidelines for all Americans to welcome their "new neighbors." Final chapter summarizes principles and goals set forth in the monograph and looks at the role that the mentally retarded citizen should have in determining how and where he shall live.

No Place Like Home: Alternative Living Arrangements for Teenagers and Adults with Cerebral Palsy. September 1975, by Irving R. Dickman. United Cerebral Palsy Associations, Inc., 66 East 34th Street, New York, New York 10016. Cost: $2.25.

This 112-page manual draws extensively upon a variety of successful models for alternative living arrangements, such as the FOKUS Society in Sweden and the Weinberger Foundation in New York. The manual suggests that there are no "permanent solutions" to the need for residential services but does present a variety of new ideas, suggestions, case histories and criteria.

Nursing Homes in the System of Residential Services: Proceedings of a National Symposium. 1975. National Association for Retarded Citizens, 2709 Avenue E East, P.O. Box 6109, Arlington, Texas 76011. Cost: $2.25.

A collection of papers enunciating basic guiding principles which can be used by parents and professionals to assess and enhance the appropriateness of nursing home settings for mentally retarded persons. Topic areas include: Standards and Regulations; Appropriateness of nursing home settings; Civil rights issues; Individual assessment and program planning; Family involvement and community interaction.

Observing in Institutions. 1974, by Robert Bogdan. Center on Human Policy or Human Policy Press, P.O. Box 127, University Station, Syracuse, New York 13210. Cost: $0.50.

A series of questions presented in this brochure are intended to serve as a guide for observing the nature of life in a variety of closed institutions; namely, state mental health facilities and state schools. The questions focus on policies, practices, programs and conditions of institutional life. Helpful hints for retention or preserving the quality of observations are also given. ("Notes from the Center, No. 2")

Operating Manual for Residential Services Personnel. 1974. Nisonger Center for Mental Retardation & Developmental Disabilities, 1580 Cannon Drive, Columbus, Ohio 43210. Cost: $4.00.

Beginning with an historical review of residential alternatives and the emergence of the group home, the first part of this manual focuses on effective administration in operating a group home. Part two gives basic information and programming for residential services personnel, followed by emergency information and procedures, along with sample forms in part three. A glossary of terms and suggested readings are also given.

Planning Alternatives to Institutions: Report on a New England Case Conference. St. Joseph's College, North Windham, Maine, January 3-5, 1975. Bureau of Mental Retardation, State Office Building, Augusta, Maine 04330. Cost: Unknown.

An overall goal of the conference was to develop meaningful strategies for implementing a deinstitutionalization plan that could be utilized not only by the State of Maine but by other states as well. Intent of the conference was to elicit, examine and deal with opinions, ideas and facts related to deinstitutionalization in a target system (Maine). Existing conditions presented problems - inadequate transportation, rural population and only one major residential institution where 80 percent of the residents are severely and profoundly retarded.

Planning for Your Own Apartment. 1975, by Virginia Sweet Belina. Fearon Publishers, 6 Davis Drive, Belmont, California 94002. Cost: $3.00.

A Program Statement for the Establishment of Community Based Residential Services for the Mentally Retarded of Montgomery County, Maryland. Montgomery County Association for Retarded Citizens (Children), 11212 Norris Drive, Silver Spring, Maryland 20902. (1971) Cost: Unknown.

Based on a policy of normalization, the MCARC residential plan calls for the establishment of a series of small, specialized community-integrated residences, dispersed throughout the county and administered within a continuum of existing non-residential services. A prerequisite to enrollment in the residential service is that the individual would be enrolled in one of the day programs in the county. Admissions would be voluntary on the part of the parent or guardian. Seven distinct types of residential facilities are outlined and summarized. Budget estimates are also given.

Report of the PARC Ad Hoc Planning Committee for Resolution II: A Design for Living. 1974. Pennsylvania Association for Retarded Citizens, 1500 North Second Street, Harrisburg, Pennsylvania 17102. Cost: Unknown.

Residential Options for Ohioans With a Developmental Disability: The Proceedings of Residential Services Seminar II. 1974. Ohio Developmental Disabilities, Inc., Suite 212, 2238 South Hamilton, Columbus, Ohio 43227. Cost: Unknown.

The purpose of the seminar, held in Columbus, Ohio, on August 15-16, 1974, and sponsored by Ohio Developmental Disabilities, Inc., was to provide an opportunity for consumers, parents, professionals and lay persons to examine the progress of Ohio's efforts to improve residential services in the past two years. Recommendations were made concerning residential models and programs, manpower, resources and training as well as specific aspects to be considered in implementing the recommendations, licensing, etc.

Returning the Mentally Disabled to the Community: Government Needs to Do More. A Report to the Congress by the Comptroller General of the United States. Washington, D.C.: U.S. General Accounting Office, January 7, 1977. (#HRD-76-152) Cost: $1.00.

This government report concludes that "Care and treatment of mentally disabled persons in communities can be an effective alternative to institutional care. However, many mentally disabled persons have been released from institutions before sufficient community facilities and services were available and without adequate planning and followup. Others enter, remain in, or reenter institutions unnecessarily."

The Right to Choose: Achieving Residential Alternatives in the Community. 1973. National Association for Retarded Citizens, 2709 Avenue E East, P.O. Box 6109, Arlington, Texas 76011. Cost: $1.50.

A resource handbook and guideline for community group action in developing residential service alternatives. Provides the underlying rationale for various types of residential programs; strategies for securing community involvement; funding and administration; program considerations; and suggestions for monitoring the service.

Standards for Community Agencies. 1973. Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, Joint Commission on Accreditation of Hospitals, 875 North Michigan Avenue, Suite 2201, Chicago, Illinois 60611. Cost: $6.50.

Standards for community agencies have been developed to emphasize the necessity of an individual program plan for each person receiving services, with each consumer and parent participating in all decisions when feasible. To promote the continuity and integration of services, standards are provided for "agency service components" rather than for specific programs that may be categorized in terms of age groups or of setting such as preschool or activity center programs. These components include individual assessment, attention to developmental needs and services to support employment and work. The Standards also include nonresidential (i.e., daytime programs) services to mentally retarded and other developmentally disabled persons.

Standards for Residential Facilities for the Mentally Retarded. 1971. Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons, Joint Commission on Accreditation of Hospitals, 875 North Michigan Avenue, Suite 2201, Chicago, Illinois 60611. Cost: $7.25.

These Standards emphasize the delivery of those services which will enable each resident to attain maximum physical, intellectual, emotional and social development. Included are standards for the professional and special services or programs that may be needed by residents. These standards are intended to be continuously reviewed and revised to maintain currency with the best thinking and practice in the field.

A Study of Alternative Community Placements. September 1976, by Richard C. Scheerenberger, Ph.D. and D. Feisenthal, M.S.W. University of Wisconsin, Madison, Wisconsin 54220. Cost: Unknown.

The general purpose of this study was to gain greater knowledge concerning the effectiveness of community placement programs. The study was based primarily on the experiences of former residents from Wisconsin's three public residential centers for the developmentally disabled.

Varieties of Residential Experience. 1975, by Jack Tizard, Ian Sinclair and R.V.G. Clarke (editors). Routledge & Kegan Paul, Ltd., Boston, Massachusetts. Cost: $20.25.

Basic rationale for residential services, including studies of staff effects on programs, comparative analysis of residential facilities and measurement methodologies are discussed in this book.

Zoning for Family and Group Care Facilities. (Planning Advisory Service Report No. 300). 1974, by Daniel Lauber and Frank S. Bangs. American Society of Planning Officials, 1313 East Sixtieth Street, Chicago, Illinois 60637. Cost: $6.00.

204

The American Society of Planning Officials surveyed a sample of 400 department planning directors in order to learn how their zoning ordinances treat these facilities. Definitions and descriptions of different social service facilities are presented as well as actual potential legal issues of current zoning treatment of family and group care facilities. Principles to be followed in determining zoning of these facilities are stated and recommendations for appropriate zoning are made.

April, 1977

Participants

ALABAMA

Harriett Tillman
Board Member
Alabama Association for
Retarded Citizens
3544 Brookwood Road
Birmingham, Alabama 95223

Jack Tillman
3544 Brookwood Road
Birmingham, Alabama 35223

ARIZONA

Ronald S. Barber
Assistant Superintendent
Department of Economic Security
Mental Retardation - Arizona
Training Program at Tucson
P.O. Box 13178
Tucson, Arizona 85732

Jeremiah R. Dandoy
District Administrator
Arizona Department of
Economic Security
Bureau of Mental Retardation
Arizona Training Program
at Phoenix
3727 East McDowell Road
Phoenix, Arizona 85008

CALIFORNIA

Dr. Tony Apolloni
Director, Model Developmental Programs
Sonoma County Association for the Retarded
1621 Cleveland Avenue
Santa Rosa, California 95401

Dick Cates
Executive Director
Sonoma County Association for the Retarded
1621 Cleveland Avenue
Santa Rosa, California 95401

Tom Cooke, Ph.D.
California State College - Sonoma
Rohnert Park, California 94928

Gerald Goff, Ph.D.
Director of Residential Programs
Marin Aid to Retarded Children
P.O. Box 55
San Rafael, California 94902

Robert M. Harrison, L.C.S.W.
Hospital Representative
Association for the Mentally Retarded
Napa State Hospital
115 Atherwood Avenue
Redwood City, California 94061

Genny Lowrie
1445 East Madison
Petaluma, California 94952

Owen R. Mock
President
Exceptional Children's Foundation
2225 West Adams Boulevard
Los Angeles, California 90018

David Peach
Chief of Residential Services
Harbor Regional Center for the
Developmentally Disabled
1201 West 220th
Torrance, California 95002

Virginia C. Robbins
Residential Care Committee
Southeast Association for Retarded
Citizens, Inc.
4049 Cortland Street
Lynwood, California 90262

Ruth P. Short
Board of Trustees
Exceptional Children's Foundation
2225 West Adams Boulevard
Los Angeles, California 90018

Robert D. Shushan
Executive Director
Exceptional Children's Foundation
2225 West Adams Boulevard
Los Angeles, California 90018

Maria Singleton
Director of Residential Services
Ukiah Valley Association for the
Handicapped
990 South Dora
Ukiah, California 95482

COLORADO

Dean Bartel
Director of Residential Services
Department of Institutions
Division for Developmental
Disabilities
3610 West Princeton Circle
Denver, Colorado 80236

Don Brandes
President
Colorado Association for Retarded Citizens
2727 Bryant Street - L3
Denver, Colorado 80211

Jackie Click
Director of Residential Services
Jefferson County Community Center
5627 Kendall Court
Arvada, Colorado 80002

Carol Lautenschlage
Staff Member
Colorado Association for Retarded Citizens
2727 Bryant Street, L3
Denver, Colorado 80211

John Lowry
Field Services Director
Colorado Developmental Disabilities
Council
770 Grant, Room 234
Denver, Colorado 80203

Dr. Daniel C. McAlees
Colorado Association for Retarded Citizens
2727 Bryant Street - L3
Denver, Colorado 80211

Doris D. Morrison
President
Ridge Association for Retarded Citizens
544 South Cody Street
Lakewood, Colorado 80226

Paul Rogers
Residential Coordinator
Adams County Center for the Retarded
3440 West 55th Avenue
Denver, Colorado 80221

Ludwig Rothbein
Director
Planning & Administration
Colorado Developmental Disabilities Council
P.O. Box 634
Denver, Colorado 80201

Jeffrey A. Sandler
Director of Planning, Evaluation
and Research
Department of Institutions
Division for Developmental Disabilities
3610 West Princeton Circle
Denver, Colorado 80236

Helen Sanks
President, Denver Association
for Retarded Citizens
701 South Logan, Suite 10
Denver, Colorado 80209

Albert Scardino
Executive Director
Colorado Association for
Retarded Citizens
2727 Bryant - L3
Denver, Colorado 80211

W.A. West
Executive Director
Denver Association for Retarded
Citizens
701 South Logan - Suite 10
Denver, Colorado 80209

CONNECTICUT

Theodore Bergeron
Executive-President
Shoreline Residential Services, Inc.
1 South Main Street
Branford, Connecticut 06405

Raymond J. Fitzpatrick
Executive Director
Waterbury Association for Retarded
Citizens
20 South Elm Street - Room 126
Waterbury, Connecticut 05702

James Morris
Shoreline Residential Services, Inc.
1 South Main Street
Branford, Connecticut 06405

Mrs. Helen B. Wallat
Administrator
Parents & Friend of Mentally Retarded

DISTRICT OF COLUMBIA

Wallace K. Babington
Director, OHI, USDHEW
290 N Street, S.W.
Washington, D. C. 20024

Carolyn Keane
Research Assistant
The Closer Look
National Information Center for
the Handicapped
1201 16th Street, N.W.
Suite 607E
Washington, D. C. 20036

FLORIDA

Robert Ettinger
Executive Director
Broward Association for Retarded
Citizens
605 S.E. 20th Street
Fort Lauderdale, Florida 33316

Roger Lunt
Planner, Evaluator
Department of Health & Rehabilitation
2908 Morningside Drive
Tallahassee, Florida 32301

Mrs. Annie McLeod
Residential Services Coordinator
Escambia County Association for
Retarded Citizens
1000 East Fairfield
P.O. Box 2427
Pensacola, Florida 32503

John Winters
Executive Director
Escambia County Association for
Retarded Citizens
1000 East Fairfield
P.O. Box 2427
Pensacola, Florida 32503

GEORGIA

Jack Blackstone, Ph. D.
Executive Director
Georgia Association for Retarded Citizens
1575 Phoenix Boulevard, Suite 8
Atlanta, Georgia 30349

Annie Joe Denny
Executive Director
Douglas County Retardation Association
8160 Dura Lee Lane
Douglasville, Georgia 30134

Mrs. Lena Belle Duke
Chairperson, Residential Services Committee
Georgia Association for Retarded Citizens
Huckleberry Hill
Fort Valley, Georgia 31030

G. Thomas Graf
Executive Director
Atlanta Association for Retarded Citizens
1687 Tully Circle, N. E., Suite 10
Atlanta, Georgia 30329

Robert Perry
Director
Annandale Village
Box 7
Suwanee, Georgia 30174

HAWAII

Diane DelosReyes
Group Home Project Director
Maui Association for Retarded Citizens, Inc.
95 Mahalani Street
Wailuku, Hawaii 96793

ILLINOIS

Sister Rosemary Connelly
Executive Director
Misericordia Home
2916 West 47th Street
Chicago, Illinois 60632

Robert Dickson
Residential Services Planner
Council of Developmental Disabilities
222 South College
Springfield, Illinois 62764

Donald Fike
Executive Director
Horizon House
2000 Plank Road
Peru, Illinois 61354

Michael W. Fortner
Executive Director
Effingham County Association for the Mentally Retarded
618 West Main Street
Teutopolis, Illinois 62467

Jan Grewell
Executive Director
Coles County Association for the Retarded
1600 B Lincoln Avenue
Charleston, Illinois 61920

Laird W. Heal
Assoc. Professor of Special Education
University of Illinois
1007 South Pine Street
Champaign, Illinois 61820

Richard Hemp
Coordinator, Community Residential Services
Region II Developmental Disabilities
W.A. Howe Developmental Center
7600 West 183rd Street
Tinnely Park, Illinois 60477

Walter Johnson
Chairman, Residential Services Committee
Illinois Association for Retarded Citizens
363 West 93rd Street
Chicago, Illinois 60620

Andrea Knight
Regional Vice President
National Association for Retarded Citizens
300 Locust Road
Winnetka, Illinois 60093

Jim Monterastelli
Clinical Coordinator
Horizon House
2000 Plank Road
Peru, Illinois 61354

Don Moss
Executive Director
Illinois Association for Retarded Citizens
6 North Michigan Avenue
Chicago, Illinois 60602

Senator John Nimrod
State Capitol Building
Springfield, Illinois 62706

Meribeth Norton
Program Director
United Cerebral Palsy of Illinois, Inc.
309 S. 3rd Street
Springfield, Illinois 62701

Sister Maria O'Leary
Misericordia Home
2916 West 47th Street
Chicago, Illinois 60632

Phyllis Pasterik
Administrator
Helping Hands Workshop
4015 Eberly
Brookfield, Illinois 60523

Mrs. Rose Poelvoorde
Executive Committee Member
Board of Directors
Illinois Association for Retarded Citizens
701 Ivy Lane
Silvis, Illinois 61282

Ann Seaman
Community Workshop and Training Center
1616 W. Barker
Peoria, Illinois 61600

T.K. Taylor
Assistant Program Director
Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons
875 North Michigan Avenue
Suite 2201
Chicago, Illinois 60611

Vivian Taylor
Executive Director
Seguin Services, Inc.
3145 South 55th Avenue
Cicero, Illinois 60650

Natalie Tessari
Workshop Director
Helping Hands Workshop
4015 Eberly
Brookfield, Illinois 60513

Ray Unterbrink
Director of Residential Services
Illinois Association for Retarded Citizens
2 Ridgeview
Springfield, Illinois 62707

INDIANA

Donald Collins
President
Indiana Association for Retarded
Citizens
115 Second Street
Shelbyville, Indiana 46176

Roger Etzler
Apartment Houseparent
Community Sheltered Workshop
P.O. Box 57
502 Weatherhead Street
Angola, Indiana 46703

Garry Fisher
Residential Services Director
Developmental Services, Inc.
422 Washington Street
Columbus, Indiana 47201

Joyce A. Hevel
Executive Director
Community Sheltered Workshop
of Stuben County
P.O. Box 57
502 Weatherhead Street
Angola, Indiana 46703

Paul Kurtz, Ph.D.
Director, Residential Services
Association for the Disabled of
Elkhart County, Inc.
P.O. Box 398
Bristol, Indiana 46507

John V. Orr
Director of Developmental Disabilities and Special Services
Catherine Hamilton Mental
Health Center
101 South 12th
Terre Haute, Indiana 47807

Sally V. Ridge
Stone Belt Council for Retarded
Citizens
3105 Browncliff
Bloomington, Indiana 47401

Russell P. Slinn
Executive Director
Lake County Association for
the Retarded
2650 West 35th Avenue
Gary, Indiana 46408

Ronald Soskin
Staff Attorney
The National Center for Law and
the Handicapped
1235 North Eddy Street
South Bend, Indiana 46617

Duane A. Stuart
Adult Services Director
Cass County Council for Mentally
Retarded Citizens
1416 Woodlawn
Logansport, Indiana 46947

Ilene Younger
Assistant Director for Public Affairs
Indiana Association for Retarded
Citizens
752 East Market Street
Indianapolis, Indiana 46202

IOWA

Mrs. Erma Bunge
Residential Care Committee
Chairperson
Linn County Association for Retarded
Citizens
1116 A Avenue N.W.
Cedar Rapids, Iowa 52405

Richard Frohm
Director of Residential Services
Polk County Association for Retarded
Citizens
421 S.W. 8th Street
Des Moines, Iowa 50309

KANSAS

Elaine P. Crowther
Director of Adult Services
Section
Kansas State Department of
Social and Rehabilitation Services
3108 Randolph
Topeka, Kansas 66611

KENTUCKY

Terry R. Brownson
Executive Director
Owensboro Council for Retarded
Citizens
P.O. Box 72
Owensboro, Kentucky 42301

Harmon T. Clingner
Executive Director
Short/Long Term Residential Care
59 Carothers Road
Newport, Kentucky 41071

Jean Gossick
Chairman, Residential Services
Kentucky Association for Retarded
Citizens
360 Queensway Drive
Lexington, Kentucky 40502

William P. McElwain, M.D.
Commissioner
Bureau of Health Services
Department for Human Resources
275 East Main Street
Frankfort, Kentucky 40601

Bob Monihan
President
Kentucky Association for Retarded
Citizens
131 Holmes Street
P.O. Box 275
Frankfort, Kentucky 40601

Carleton D. Scully
Executive Director
Blue Grass Association for
Retarded Citizens
898 Georgetown Street
Lexington, Kentucky 40505

LOUISIANA

Ray Barnes
Executive Director
Greater New Orleans Association
for Retarded Citizens
5700 Loyola
New Orleans, Louisiana 70115

Corinne F. Barnwell
Coordinator
Citizen Advocacy Program
Greater New Orleans Association
for Retarded Citizens
7100 St. Charles Avenue
New Orleans, Louisiana 70118

Dorothy K.J. Campbell
President
Lake Charles Association for
Retarded Citizens
315 Glenn Street
Lake Charles, Louisiana 70601

Joe Cerise, Ph.D.
Assistant Superintendent
Hammond State School
Rt. #3 - Box 165 P
Hammond, Louisiana 70401

William M. Coffey
Assistant Director
Division of Mental Retardation, LHHRA
721 Government Street, Room 306
Baton Rouge, Louisiana 70802

Dorothy Daley
President
Parents Association at Northwest
State School
10290 West Winston - Apt. #1
Baton Rouge, Louisiana 70809

Dr. Maurice Dayan
P.O. Box 191
Pineville. Louisiana 71360

Jerome P. Dickhaus
President
Greater New Orleans Association
for Retarded Citizens
5700 Loyola
New Orleans Louisiana 70115

Michael Eby
Immediate Past President
Iberville Association for
Retarded Citizens
1608 Maple Street
Plaquemine, Louisiana 70764

Otto P. Estes, MSW
Member
American Association on
Mental Deficiency
721 Government Street
Room 306
Baton Rouge, Louisiana 70802

George E. Fryer
433 Metairie Road
Suite 215
Metairie, Louisiana 70005

William S. Gannaway
President
Ouachita Association for Retarded
Citizens
1311 7th Street
Municipal Airport
Monroe, Louisiana 71203

Nancy Haslett, M.D.
Pediatric Neurologist
Louisiana State University
Medical Center
New Orleans, Louisiana 70112

Randall Hixson
Director of Training
Health Care Center of Alexandria
P.O. Box 1827
Alexandria, Louisiana 71301

George D. Huie
Coordinator of Child Life
Magnolia School, Inc.
237 Central Avenue, Apt. #2
Jefferson, Louisiana 70121

Patrick F. McGinnis
Executive Director
Caddo-Bossier Association for
Retarded Citizens
351 Jordan
Shreveport, Louisiana 71101

Douglas McWhirter
Director of Social Services
Residential Facilities for Mentally
Retarded
Volunteers of America
P.O. Box 37
Baton Rouge, Louisiana 70821

Sarah Morrison
Assistant Director
Exceptional Children's Program
4155 Essen Lane, Apt. #132
Baton Rouge, Louisiana 70809

G. Ross Murrell, Jr., A.I.A.
Associate Architect
O'Rourke-Gossen & Associates
Architects/Engineers
104 Live Oak Drive
Lafayette, Louisiana 70503

Mrs. Delores O'Keefe
Board Secretary
Louisiana Association for Retarded Citizens
7465 Exchange Place
Baton Rouge, Louisiana 70806

Mrs. Marian Rounds
President-Elect
Louisiana Association for Retarded Citizens
5120 Shelley Drive
Baton Rouge, Louisiana 70805

Mrs. Carrie Saia
Executive Director
Louisiana Association for Retarded Citizens
7465 Exchange Place
Baton Rouge, Louisiana 70806

Helen F. Weinstein
Coordinator of Institutional Services
2100 College Drive - #101
Baton Rouge, Louisiana 70808

MAINE

Kevin C. Baack, Ph.D.
Director
Bureau of Mental Retardation
Room 411
State Office Building
Augusta, Maine 04333

MARYLAND

Lou Chapman
Director of Membership and Program Services
Maryland Association for Retarded Citizens
55 Gwynns Mill Court
Owings Mills, Maryland 21117

B. Richmond Dudley
Member
Developmental Disabilities Council
201 West Preston Street
4th Floor
Baltimore, Maryland 21201

Roger L. Harrell
State of Maryland
Mental Retardation Administration
201 West Preston Street
Baltimore, Maryland 21201

Jerry Kiracofe
Director of Residential Programs
Baltimore Association for Retarded Citizens
4800 York Road
Baltimore, Maryland 21212

Terry Perl
Executive Director
Chimes, Inc.
1803 Thornbury Road
Baltimore, Maryland 21209

Sherry Smith
Washington County Association for Retarded Citizens
Route #1
Smithburg, Maryland 21783

Mike Spurgin
Executive Director
Washington County Association for Retarded Citizens
Route #1
Smithburg, Maryland 21783

Betty Whilden
Chairman
Residential Services Committee
Maryland Association for Retarded Citizens
55 Gwynns Mill Court
Owings Mills, Maryland 21117

MASSACHUSETTS

Charlotte Aladjem
Board Member
Massachusetts Association for
Retarded Citizens
3 Field Road
Lexington, Massachusetts 02173

Don Anderson
Director
Office of Program Services
Division of Mental Retardation
Department of Mental Health
Commonwealth of Massachusetts
190 Portland Street, 4th Floor
Boston, Massachusetts 02114

Elizabeth Anderson
Federation for Children with
Special Needs
120 Boylston Street
Boston, Massachusetts 02169

Gunnar Dybwad
Professor of Human Development
Brandeis University
Heller School
Waltham, Massachusetts 02154

Elinor Gollay
Member
Massachusetts Association for
Retarded Citizens
Abt Associates
55 Wheeler Street
Cambridge, Massachusetts 02238

Ann MacEachron
Assistant Professor, Coordinator
Mental Retardation Research
Heller School Brandeis University
Waltham, Massachusetts 02154

Susan Rubenstein
Assistant Director of Mental
Retardation
Division of Mental Retardation
Department of Mental Health
190 Portland Street
Boston, Massachusetts 02114

MICHIGAN

Mary Brimhall
[illegible]-Chairperson
Residential Services Committee
Michigan Association for Retarded
Citizens
416 Michigan National Tower
Lansing, Michigan 48933

Dennis Ferkany
President
Residential Systems Company
516 West University
Rochester, Michigan 48063

Dorothy Moser
President
Michigan Association for Retarded
Citizens
1854 Emerald, N.E.
Grand Rapids, Michigan 49505

Agnes Smith
Community Services Consultant
Michigan Association for Retarded
Citizens
416 Michigan National Tower
Lansing, Michigan 48933

MINNESOTA

Daniel J. Connor
Executive Director
Greenbrier Home, Inc.
941 Birmingham Street
St. Paul, Minnesota 55106

Bradley Hill
Education Director
Rubin Lind Learning Center
University of Minnesota
101 Pattee Hall
Minneapolis, Minnesota 55455

Clyde Johnson
Executive Director
Duluth Regional Care Center
1504 Alworth Bldg.
Duluth, Minnesota 55802

Arlan Kakac
Program Director
Project New Hope, Inc.
Box 595
Alexandria, Minnesota 56308

Charles Kroeger
Administrator
Q.S.S., Inc.
122 N.W. 7th Street
Faribault, Minnesota 55021

Toni Lippert
Developmental Disability Planner
State of Minnesota
Metro Health Board
300 Metro Square Building
St. Paul, Minnesota 55101

Martin McGraw
Warner Care Homes, Inc.
Cokato, Minnesota 55321

Robert Ortquist
Warner Care Homes, Inc.
Cokato, Minnesota 55321

Kathryn R. Roberts
Technical Assistance Project
Consultant
Mental Retardation Program
Office
State of Minnesota, Department
of Public Welfare
Centennial Office Bldg.
658 Cedar Street
St. Paul, Minnesota 55155

Skip Sajevic
Executive Director
Nor-Haven
1394 Jackson
St. Paul, Minnesota 55117

Jerry Walsh
Executive Director
Mt. Olivet Rolling Acres
Rt. #1 - Box 576
Excelsior, Minnesota 55331

John L. Warner
Administrator
Warner Care Homes, Inc.
Cokato, Minnesota 55321

MISSISSIPPI

Paul D. Cotten, Ph.D.
Director
Ellisville State School
Ellisville, Mississippi 39437

Jean Denney
3000 25th Street
Meridian, Mississippi 39301

Camille Foretich
Resource Director
Harrison County Association for
Retarded Citizens, Inc.
P.O. Box 597
828-A Pass Road
Gulfport, Mississippi 39501

Anne T. Hamilton
Box 932
Meridian, Mississippi 39301

MONTANA

Nancy Dodd
Assistant Professor
Director of the Career Advancement Program
University of Montana
239 A S.U.B.
1500 North 30th
Billings, Montana 59101

Terri O'Fallon
Executive Director
Regional Community Services for Developmental Disabilities
2204 Beloit
Billings, Montana 59101

Sue Jackson
Developmental Disabilities Specialist - SRS
State of Montana
25 South Ewing
Helena, Montana 59601

Donald K. Reed
Assistant Director
Regional Services for the Disabled
Regional Vice President
Montana Association for Retarded Citizens
P.O. Box 1171
3907 1st Avenue South
Billings, Montana 59103

NEBRASKA

Dave Howard
Executive Director
Eastern Nebraska Community Office of Retardation (ENCOR)
885 South 72nd Street
Omaha, Nebraska 68114

David W. Powell
Executive Director
Nebraska Association for Retarded Citizens
620 North 48th, Suite 318
Lincoln, Nebraska 68504

Carl Sullivan
Chairperson, Human and Legal Rights to Residential Services Committee
Nebraska Association for Retarded Citizens
140 South 40th Street
Omaha, Nebraska 68131

NEVADA

David V. Edwards
Assistant Administrator for Mental Retardation
State of Nevada
Division of Mental Hygiene and Mental Retardation
4600 Kietzke Lane, Suite 108
Reno, Nevada 89502

NEW JERSEY

Elizabeth M. Boggs, Ph.D.
Member, NARC Governmental Affairs Committee
R.D. #1 - Box 439
Hampton, New Jersey 08827

Claire M. DeRoner
Planning Officer
New Jersey Division of Mental Retardation
Department of Human Services
264B - R.D. #1
Annandale, New Jersey 08801

Mrs. Mary Ann Walsh
Executive Director
Morris Unit
New Jersey Association for
Retarded Citizens
38 Elm Street
Morristown, New Jersey 07960

Clarence N. York, Ed.D.
Director
The Bancroft School
Hopkins Lane
Haddonfield, New Jersey 08033

NEW MEXICO

Opal Moore
Vice President - District II
New Mexico Association for Retarded Citizens
Box 4
Broadview, New Mexico 88112

Charlotte Nolet
Director of Social Services
Eastern New Mexico Rehabilitative Services for the Handicapped
Box 1706
Clovis, New Mexico 88101

NEW YORK

Karl Heiner
Instructor, Teachers College
Columbia University
Box 82
525 West 120th Street
New York, New York 10027

Theodore E. Johnson
Executive Director
People - Service to the Retarded
Adult, Inc.
1552 Hertel Avenue
Buffalo, New York 14216

Ernest Weinrich
Coordinator
Planning for Long Term Service
United Cerebral Palsy Assns., Inc.
66 East 34th Street
New York, New York 10016

NORTH CAROLINA

Mrs. Julie Ewing
Executive Secretary
Alamance County Association for
Retarded Citizens
2515 Hickory Avenue
Burlington, North Carolina 27215

Rose M. Forrest
Area Coordinator of Developmental
Disabilities
Gaston-Lincoln Area Mental Health
Program
P.O. Box 1474
Gastonia, North Carolina 28052

Jerry W. Hyde, Sr.
Treasurer
Piedmont Residential Development
Center, Inc.
508 Dunlap Street
Kannapolis, North Carolina 28081

Becky McRorie
Chairperson, Board of Directors
Piedmont Residential Development
Center, Inc.
567 Crestmont Drive
Concord, North Carolina 28025

Stephen Ramey
Area Developmental Disabilities
Specialist
Piedmont Area Mental Health Centers
P.O. Box 1050
Concord, North Carolina 28025

Vicki H. Waddell
Developmental Disabilities Coordinator
Piedmont Area Mental Health
Cabarrus Center
315 Rosemont Avenue, S.E.
Concord, North Carolina 28025

Doreen M. Weston
Administrative Director
Ralph Scott Group Homes, Inc.
P.O. Box 1001
Burlington, North Carolina 27215

NORTH DAKOTA

Erling N. Sannes
2033 St. Bennedict
Bismarck, North Dakota 58501

George Zenk
Director of Habilitation
Grafton State School
Grafton, North Dakota 58237

OHIO

Frank Kimber
Associate Director - Health
Federation for Community Planning
1001 Huron Road
Cleveland, Ohio 44115

Robert Knable
Executive Director
Developmental Disabilities
Resources, Inc.
2238 South Hamilton Road
Columbus, Ohio 43227

Mrs. Nina Mervine
Residential Services Chairman
Ohio Association for Retarded
Citizens
465 Stanley Road
Akron, Ohio 44312

Robert Miller
Executive Director
Ohio Association for Retarded
Citizens, Inc.
8 East Long Street - 9th Floor
Columbus, Ohio 43215

Ray Thomas
Executive Director
Summit County Association for
Retarded Citizens
137 East Avenue
P.O. Box 38
Tallmadge, Ohio 44278

Walter Vborowsky
Executive Director
Help for Retarded Children
13032 Euclid
East Cleveland, Ohio 44112

OKLAHOMA

Charles Streamer
VISTA Volunteer
Muskogee Association for Retarded
Citizens
915 North Utah
Muskogee, Oklahoma 74401

OREGON

Peter Engbretson
Residential Care Facility Coordinator
Department of Public Safety
Residential Care Facilities
City of Portland
Portland, Oregon 97204

Eleanor Johnson
President
Oregon Association for Retarded
Citizens
3085 River Road North
Salem, Oregon 97303

Senator William McCoy
Oregon State Senate
6650 North Amherst Street
Portland, Oregon 97203

Eleanor Miller
Chief, MR/DD Community Residential Programs
State of Oregon
Mental Health Division
2575 Bittern Street, N.E.
Salem, Oregon 97310

PENNSYLVANIA

Mrs. Marlene Burda
Chairman
Residential Services Committee
Pennsylvania Association for
Retarded Citizens
107 Ida Drive
Glenshaw, Pennsylvania 15116

Mrs. Elsie Schmidt
President
Pennsylvania Association for
Retarded Citizens
Box 393
R.D. #3
Leechburg, Pennsylvania 15656

Charles A. Stanford
President
Mercer County Association for
Retarded Citizens
c/o TV Times
P.O. Box 483
Clark, Pennsylvania 16114

Jeffrey L. Strully
Staff Member
Pennsylvania Association for
Retarded Citizens
3032 Guineveer Drive
Harrisburg, Pennsylvania 17110

RHODE ISLAND

Alina Sargent
160 Oliphant Lane
Middletown, Rhode Island 02840

Ken Sargent
Director
Newport County Chapter
Rhode Island Association for
Retarded Citizens
160 Oliphant Lane
Middletown, Rhode Island 02840

SOUTH CAROLINA

Darrell T. Johnson
Director, Rehabilitation Services
South Carolina Department of
Mental Retardation
P.O. Box 4706
2712 Middleburg Drive
Columbia, South Carolina 29240

Mrs. Jill Taylor
Executive Director
Spartanburg County Association for
Retarded Citizens
458 North Church Street
Spartanburg, South Carolina 29303

TENNESSEE

Jill Copeland
Doctoral Student
123 Fairway Drive
Nashville, Tennessee 37214

Paula M. Cyr
Placement Coordinator
State of Tennessee
Clintonbottom Developmental Center
150 Hickorydale Drive
Nashville, Tennessee 37210

Harris Dobkin
Doctoral Student
123 Fairway Drive
Nashville, Tennessee 37214

Ruth Dobkin
Special Education Teacher
Gallantin School District
123 Fairway Drive
Nashville, Tennessee 37214

Glenda J. Huff
Program Analyst
Department of Mental Health
and Mental Retardation
4th Floor
502 Union Building
Nashville, Tennessee 37219

Jane A. Watson
Coordinator of Outreach
Arlington Developmental Center
2224 Forrest Hills, Apt. #8
Memphis, Tennessee 38134

TEXAS

Cecil O. Campbell, Ph. D.
Administrator of Residential
Services
Fort Worth State School -
TDMHMR
500 Campus Drive
Fort Worth, Texas 76119

Jack English
Project Coordinator
South Central Regional Center
for Services to Deaf-Blind
Children Program
The University of Texas at
Dallas
Callier Center
1966 Inwood Road
Dallas, Texas 75235

Alice B. Golan
Staff Assistant
Social Security Administration
Bureau of Supplemental Security
Income Regional Office
7409 Wellcrest Drive
Dallas, Texas 75230

Ellen J. Huffman
Chairman
Dallas-Tarrant County ARCs'
Residential Services Committee
Fort Worth-Dallas Association for
Retarded Citizens
3520 Ingleside Drive
Dallas, Texas 75229

Erwin Jaloway
Director of Mental Retardation
Nueces County MH/MR Community
Center
1630 South Brownlee
Corpus Christi, Texas 78404

Mrs. Bernadette Jenney
State Secretary and Co-Chairperson
State Affairs Task Force
Texas Association for Retarded
Citizens
1605 Westcrest Drive
Arlington, Texas 76013

Mrs. Gene Karaffa
President
Texas Association for Retarded
Citizens
3021 North 43rd Street
Waco, Texas 76710

John Lucas
Director
Blind-Mentally Retarded Program
Center for Applied Research &
Evaluation
2004 Buffalo Terrace
Houston, Texas 77019

Jane Markowitz, Ph.D.
Member
Board of Directors
San Antonio Association for
Retarded Citizens
227 West Drexel Street
San Antonio, Texas 78210

Bill Moore
Coordinator of Residential
Services for Trinity Valley
MH/MR Authority
6745-B #21 Calmont
Fort Worth, Texas 76116

David B. Sloane
Executive Director
Texas Association for Retarded
Citizens
833 Houston
Austin, Texas 78756

Beverly Soholt
Executive Director
Midland Association for Retarded
Citizens
2501 Bedford
Midland, Texas 79701

John B. Williams
Extended Services Specialist
The University of Texas at Dallas
Callier Center
South Central Regional Center for
Services to Deaf-Blind Children
Program
1966 Inwood Road
Dallas, Texas 75235

UTAH

Eric Moon
Project Director
Project TURN
2952 South 7th East
Salt Lake City, Utah 84106

VERMONT

William H. Abraham
President
Champlain Association for Retarded
Citizens
Box 341
Shelburne, Vermont 05482

Eric T. Grims
Developmental Disabilities Facilitator
Northeast Kingdom Mental Health
Box #35
Derby Line, Vermont 05830

Ronald Melzer, Ph.D.
Director
Division of Mental Retardation
Vermont Department of Mental Health
79 River Street
Heritage II
Montpelier, Vermont 05602

Sister Janice E. Ryan
Executive Director
Vermont Association for Retarded
Citizens
323 Pearl Street
Burlington, Vermont 05401

John J. Sawyer
Executive Director
Guardianship Trust of Vermont, Inc.
P.O. Box 302
Montpelier, Vermont 05602

Joan Sylvester
Executive Secretary
Vermont Association for Retarded
Citizens
323 Pearl Street
Burlington, Vermont 05401

VIRGINIA

Nancy Antonides
Director of Residential Programs
Insight, Inc.
Box 1196
Manassas, Virginia 22110

Joni Fritz
Executive Director
National Association of Private
Residential Facilities for the
Mentally Retarded
6269 Leesburg Pike - Suite B-5
Falls Church, Virginia 22044

William C. Geer
Executive Director
The Council for Exceptional
Children
1920 Association Drive
Reston, Virginia 22091

John F. Haack
Director
Developmental Disabilities Unit
Virginia State Department of Mental
Health & Mental Retardation
1108 East Main Street - Suite 400
Richmond, Virginia 23219

Doris Haar
Director of Research & Development Division
Developmental Disabilities Office
Department of Health, Education
and Welfare
2301 South Jefferson Davis Highway
Apt. #1133
Arlington, Virginia 22202

WEST VIRGINIA

John E. Barnette
Executive Director
Shawnee Hills Regional Center, Inc.
P.O. Box 338
Institute, West Virginia 25112

Janie Marie Lambert
Developmental Disabilities Program
Planning Specialist
West Virginia Commission on Mental
Retardation
206-A Terrace Park East
2106 Kanawha Boulevard
Charleston, West Virginia 25311

David M. McWatters
Director of Administration
Shawnee Hills Regional Center
P.O. Box 338
Institute, West Virginia 25112

WISCONSIN

Mary Coffee
Member, Residential Services Committee
United Association for Retarded
Citizens
611 East Wells Street
Milwaukee, Wisconsin 53202

Patrick J. Flanigan, Ph.D.
Association Director
Rehabilitation, Research and Training
Institute
Waisman Center
University of Wisconsin
2605 Marsh Lane
Madison, Wisconsin 53706

Merlen G. Kurth
Executive Director
Wisconsin Association for Retarded
Citizens
2700 Laura Lane
Middleton, Wisconsin 53562

John Lobenstein
Chief of Community and
Residential Services
Wisconsin Division of Mental
Hygiene
1 West Wilson Street - Room 540
Madison, Wisconsin 53702

Gilbert J. Mauthe
Executive Director
New Concepts for the Handicapped
Foundation, Inc.
126 South Franklin Street
Madison, Wisconsin 53703

David G. Merriam
Staff Attorney
Wisconsin Association for Re-
tarded Citizens
2700 Laura Lane
Middleton, Wisconsin 53562

Rep. Mary Lou Munts
Wisconsin State Legislature
9 West State Capitol
Madison, Wisconsin 53702

Mary Murphy
Chairperson
Council on Developmental Disabilities
c/o Wisconsin Association for
Retarded Citizens
2700 Laura Lane
Middleton, Wisconsin 53561

Dale Toltzman
Regional Administrator
New Concepts Foundation
126 South Franklin Street
Madison, Wisconsin 53703

David Zelman, Ph.D.
Regional Administrator
New Concepts Foundation
126 South Franklin Street
Madison, Wisconsin 53703

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1977

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NARC Research and Demonstration Institute
National Association for Retarded Citizens
2709 Avenue E East, P.O. Box 6109
Arlington, Texas 76011

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